THE EXPERIENCE OF CHINESE PARENTS OF CHILDREN WITH ACUTE LYMPHOCYTIC LEUKAEMIA (ALL)

By

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ABSTRACT

Advances in the treatment of childhood malignancies especially in the case of Acute Lymphocytic Leukaemia have dramatically increased the survival rate of such children. In Hong Kong, very little is known about the effects of ALL on parents. The purpose of this study is to explore the experiences of Hong Kong Chinese parents with children suffering from acute lymphocytic leukaemia (ALL). A qualitative approach was used to collect data and interviews were undertaken using a semi-structured interview guide developed by the researcher. A total of nine mothers and eight fathers contacted through referral participated in the main study and were interviewed separately on two occasions by the researcher. The initial interview was scheduled four weeks after the confirmation of ALL and the second interview was scheduled after the completion of induction therapy. The two interviews were scheduled to coincide with the disease trajectory of ALL, thus allowing the researcher to compare the parents' experiences during two different treatment phases. Each parent was interviewed in Cantonese and the responses were later transcribed and translated into English. The matrix system described by Miles and Huberman (1994) was used to display and analyse the research data. Major categories of parental reactions when the diagnosis of ALL was confirmed, methods used to disclose the child's diagnosis to members of both the immediate family, extended family and

others, changes in the family routine, reactions and sources of support were identified. Parents' initial reactions were both physical and psychological in nature, both fathers and mothers stated that the suddenness of the diagnosis of ALL in their previously healthy children made it difficult for them to accept. Siblings were told of the child's actual diagnosis if they were over 10 years old otherwise partial truth was told. Members of the extended families were informed if they could provide actual assistance to the parents. The majority of mothers cited the spouse as their main source of support, followed by health care professionals and friends. Religious belief was cited as a source of support by more fathers than mothers. Uncertainty about the efficacy of treatment and the child's future were also concerns for some of the mothers. Parents' experiences became more positive as treatment progressed and the children responded well. The experiences of Chinese parents of children with ALL are similar to those of parents in other countries. The results of this study provide information about parental experiences associated with the different phases of the child's illness, which can be used to inform nursing interventions. Implications for health professionals include a need for thorough psychosocial assessment of children, parents and siblings. In addition, collaboration between medical and nursing personnel would also be helpful in the provision of comprehensive care to these children and their parents.

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Introduction

Although childhood cancers rank second only to accidents as a leading cause of death in children (Nicholson, 1990; Aitken & Hathaway, 1993), advances in the field of pediatric oncology have dramatically changed the outcome of childhood cancers in the past thirty years. The disease was once considered a rapidly fatal illness, with an average life expectancy of 19.3 weeks for children diagnosed with acute lymphocytic leukaemia in the 1950s (Bozeman, Orbach & Sutherland, 1955), but this is no longer the case. Most children diagnosed with cancer are surviving more than five years (Bleyer, 1990), and over 60% of such children today attain a disease free status (McGuire & Moore, 1990; Gamis & Nesbit, 1991).

Of all the childhood malignancies, leukaemia is the most common type of childhood cancer accounting for 34% of all childhood cancers in the United States of America (Bleyer, 1990) and 32.9% in Hong Kong (Leung, 1994). With advances in medical knowledge and in particular radiotherapy and chemotherapy, the survival rate of children with cancers has greatly improved. Due to the increased utilization of intensive chemotherapeutic protocols, the survival rate of children suffering from acute lymphocytic leukaemia (ALL) now exceeds 70% (Gamis & Nesbit, 1991). Children who are diagnosed with a less aggressive type of leukaemia have a cure rate of 90% (Chauvenet & Wofford, 1990).

A survey of literature written on childhood cancers in the 1950s, 1960s and the early 1970s reflects the poor prognosis of the disease at that time. Literature focused on the families' coping strategies with regard to the dying child and preparing the parents for the impending death of the child. There was a heavy emphasis on parental bereavement, due to the high mortality rate of the children (Bozeman et al., 1955), and on how the physician could help the parents to cope with the anticipatory loss of their child (Friedman, 1967).

In 1973, Binger wrote:

> "Diagnostic tests revealed that Jimmy had a fatal disease - acute leukaemia..... the hematologist proceeded to answer their questions concerning the diagnosis, anticipated course of illness, treatment, and its fatal prognosis....." (Binger, 1973:172).

Most of the studies conducted during this period involved assessing the mothers' reactions to the child's diagnosis of cancer and the mothers' coping mechanisms. Research was deficient in the study of the fathers' experience, as fathers were often not available to participate in the study because of their work commitments (Bozeman et al., 1955). Fathers generally declined to be interviewed when they came to visit their child after work because they did not want the researchers to impinge on their limited time with the child (Bozeman et al., 1955; Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969). With an improved survival rate attained through medical technology, Wilbur (1975) argued that medical professionals needed to recognize the importance of rehabilitating both children diagnosed with cancer and their families.

Wilbur further argued that without successful rehabilitation of these children and their families, successful treatment of the tumour would have little meaning. Wilbur's argument was supported by Mauer (1987) who stated that it is more appropriate for the focus of research on childhood cancers to shift from the grieving processes to that of recovery, adaptation and rehabilitation of children and families.

Indeed, childhood cancers now have a greater chance of cure due to the changing patterns of the disease. The treatment may span two or three years as in the case of ALL (Chauvenet & Wofford, 1990). Despite the improved survival rate of children with cancer, the diagnosis of cancer remains a stressful event and threatens not only the child but the entire family (Fife, Huhman & Keck, 1986; Peace, O'Keeffe, Faulkner & Clark, 1992). Casileth and Hamilton's (1979) description of cancer as a "family disease" still applies, and their argument that cancer imposes change and disrupts the family's functioning remains true (Herbst, 1989; Walsh-Burke, 1992). Chesler and Barbarin (1987) further referred to cancer as a "community disease", as the diagnosis of cancer is often an unexpected crisis which affects the entire family with parents requiring help from the community to cope. Disruption in the family following the diagnosis of cancer can result in marital difficulties and sibling rivalry within the family (Lansky, Cairns, Hassanein, & Lawman, 1978; Martinson & Cohen, 1989). The possibility of relapse and death during and after therapy for ALL remains a threat to the children and their families. Koocher & O'Malley (1981) named this uncertainty the "Damocles Syndrome". Studies have been carried out to try to gain a

better understanding on the effect of chronic uncertainty on children who have completed treatment, their siblings and parents (Cohen & Martinson, 1988; Clark-Steffen, 1993).

In order to provide comprehensive, good quality care to children with cancer and their families, it is of prime importance to understand the experiences of the parents of such children, as they play a vital role in supporting their children throughout the whole disease process. With the treatment span of ALL lasting two to three years, most of the treatment is given on an outpatient basis. Children with ALL are dependent on and supported by significant others, most notably parents and the siblings. The parents are usually the main caregivers for these children (Aitken & Hathaway, 1993; Wright, 1993). Researchers from the United States have studied the problems encountered by Caucasian parents and their children during the initial and terminal phases of the disease (Spinetta, 1982; Moore, Krammer & Perin, 1986; Singleton, 1992), but there have been very few published studies that explore the views of parents from other cultural groups (Martinson & Liang, 1992). Cultural as well as social factors play a significant role in one's perception of illness, quality of relationships, and attitudes towards life and death (Die Trill & Holland, 1993). Phillips & Pearson (1996) suggest that Hong Kong Chinese are influenced by both Western and Chinese cultures and as such the reactions of Hong Kong Chinese parents of a child with ALL may be different to Caucasian parents. Therefore, in view of a lack of research into families in Hong Kong and in particular into exploring the

fathers' perspective, it is the intention of the researcher to explore and gain a better understanding of the experiences of such parents. Nurses need to understand the impact of cancer on the affected children and their families as they spend the most time with the family during the frequent hospitalisations and clinic visits of the children. Increased knowledge of how Chinese parents react to having a child diagnosed with cancer, and their potential sources of support in coping with the disease will be helpful to nurses and other health care professionals in the provision of high quality care to these children and their families.

Chapter 2

Review of Literature

The literature review provides a comprehensive review of clinical papers, research studies and theoretical writings published within the past ten years that focus on the family's experience with childhood cancers. Particular emphasis has been given to articles about parental experiences with the illness. Pioneering and seminal work from before this period has also been included. Several important issues emerged from the literature review which reflect the developments in the treatment of childhood cancers and which have produced significant changes in the natural patterns of the disease. The first of these is the parental response to the diagnosis of cancer and in particular the responses of parents of children with ALL. Secondly, the impact of the treatment period on the parents. Thirdly, the sources of support utilized by the parents and fourthly the coping strategies utilized by the parents during the treatment phase. Finally how the family and in particular the parents cope with the uncertainty of the disease as it progresses and the long term side effects resulting from the disease and therapy are reviewed. Researchers who investigated parental reactions at the onset of their child's illness seem to favour a qualitative approach using interviewing as the method of data collection (Clements, Copeland & Loftus, 1990) whereas researchers who followed the parents' experience throughout the child's illness used a

combination of both qualitative and quantitative approaches (Birenbaum, 1990; Lozowski, Chesler & Chesney, 1993).

Parental Responses to the Diagnosis of Acute Lymphocytic Leukaemia (ALL)

The first issue discussed widely related to research into parental responses to the effect and impact of ALL and these studies has been conducted since the mid 1950s. The focus of research at that time reflect the poor prognosis of childhood cancer in as much as the aim of this research was to assess the impact of ALL on the parents, offer support and prepare the child and the parents for the imminent death of the child. Classical studies carried out by Bozeman et al. (1955) and Friedman, Chodoff, Mason & Hamburg (1963) reported that the diagnosis of ALL in these children implied a chronic, fluctuating but invariably fatal illness. In the study by Bozeman et al., multiple in-depth interviews, observations of mothers interacting with their children and the Thematic Apperception Test were used to evaluate the mothers' adaptation to the threatened loss of their child. Bozeman and her colleagues reported that all twenty mothers in the study expressed emotions such as anxiety, denial, grief, anger, hostility and disbelief at the time the diagnosis of cancer was made and stated that the time of diagnosis was most stressful for them. The report that diagnosis is the most stressful time for many parents is supported by many empirical studies of childhood cancer (Binger et al., 1969; Schuler, Bakos, Zsamber, Polcz, Koos, Kardos & Revesz, 1985; Brown, 1989; Lozowski et al. 1993).

The findings of the study by Bozeman et al. demonstrated with the progression of disease and as the children attained remission after the initiation of induction therapy, some mothers became more hopeful and believed that their child had a chance to be cured, thus the fear of losing their child was temporarily suspended. Although all the mothers were initially interviewed at the time of their child's first hospitalization and the Thematic Apperception Test (TAT) was administered to only nine mothers as the rest were too distressed to participate towards the end due to their children's' deteriorating conditions. The TAT is a projective psychological test devised by Morgan and Murray (Rudin, Martinson & Gilliss, 1988) that entails the presentation of a series of pictures depicting ambiguous content to reveal information about the mothers' emotions and needs which are based on past experience. Through content analysis of the imaginary stories the researchers were able to ascertain the influence of the child's' illness and past experiences on the interpretation of the pictures. The TAT, which provides visual stimuli for the mothers and may elicit different kinds of data, is an appropriate test to obtain information about emotion-related concerns of the mothers (Rudin et al, 1988).

Although Bozeman and her colleagues only interviewed and observed mothers of children with ALL in their study, they suggested that findings from their study applied to both mothers and fathers as no information was available about the reactions of fathers of dying children. This exclusion of fathers from the study forced the researchers to extrapolate their findings from the mothers to the fathers. The findings

from Bozeman et al's study that both fathers and mothers of a child with ALL underwent similar experiences was not supported by Townes, Wold & Holmes' longitudinal three year study conducted between 1965 and 1967. In this seminal work Townes et al. (1974) utilized a repeated measures design to evaluate the adaptation of seven sets of parents whose children were under treatment for leukaemia. Three questionnaires pertaining to adult mourning were sent to parents' homes at yearly intervals along the disease trajectory. Parents were asked to fill out the questionnaires and return them by mail. The findings from the study suggested that fathers followed the typical tri-phasic pattern of anticipatory mourning but the mothers tended to report sustained negative feelings throughout the course of the disease with no relief after the death of the child. The differences between the fathers' and mothers' adaptation process suggest that fathers may accept the reality relating to the potential loss of the child early on, thus accomplishing their work of mourning prior to the death of the child. Thus it would appear that mothers in Towne et al's study utilised denial as a defense mechanism much more than the fathers. In addition to the small sample size in Townes et al's study, the claims that mothers were more affected by the child's death could have been better studied using a qualitative approach as little was known about parental coping at that time. The use of denial undoubtedly helped the mothers to cope at the onset of the child's diagnosis but hindered their mourning process when the child eventually died.

Fife, Norton & Groom (1987) utilized validated self-report instruments to study thirty four sets of parents with children with leukaemia prospectively one year after diagnosis and found that parental anxiety slowly decreased over the year. The study is primarily descriptive in nature and provides no clear link between family characteristics and parental anxiety level. It would therefore be useful to evaluate parental anxiety systematically over time using standardized tests developed for assessing parents' anxiety levels longitudinally, however no published tests are available to date. It would be more appropriate to interview these parents longitudinally to assess any changes in their anxiety level.

Disclosure Of The Child's Diagnosis

This first category contains another important issue: whether or not parents should disclose the child's diagnosis to the child concerned and the rest of the family. Research in this area suggests that this decision creates much stress for the parents of newly diagnosed children (Share, 1972; Chesler & Barbarin, 1987; Martinson, Su & Liang,1993).

Koocher & O'Malley (1981) interviewed 36 parents and demonstrated that families whose members communicated openly about the diagnosis and prognosis adjusted better during the course of the child's illness. If family members are able to communicate openly, the need to change family routines because of the affected

child's treatment regime will be better understood and tolerated by other members of the family. Communication among family members is therefore an important issue which has received much attention in the literature. A survey of the literature clearly revealed that deliberations about whether or not the child and members of the family should be told of the diagnosis were of major concern to many parents (Binger et al. 1969; Van Dongen-Melman & Sanders Woudstra, 1986; Chesler & Barbarin, 1987).

Both the protective approach and the open approach to telling the child with cancer about his diagnosis were favoured by various researchers (Toch, 1964; Waechter, 1971; Slavin, O'Malley, Koocher & Foster, 1982). The relative risks and benefits of both approaches have been debated by various researchers, with the open approach having attained greater popularity recently (Chesler & Barbarin, 1987).

Toch (1964), based on his observations of parents of children with cancer, suggested that it was best to conceal the diagnosis from the child and the family. Toch (1964) wrote:

> "The happiest survivals that I have seen were in children where the family was able to treat them just as if nothing had happened, where the parents mask their adjustment to their child's disease, tucked it away in the back of their minds, and then went on living"(pp. 421).

Observations by Toch (1964) and by Howell (1966), supported the choice of hiding the diagnosis of cancer from the child and other members in the family. The intention of these parents was to protect the child, especially at a time when the child

had just been diagnosed with a life-threatening illness (Van Dongen-Melman & Sanders Woudstra, 1986). However, not all researchers share this view and some have challenged it (Binger et al., 1969; Waechter, 1971; Slavin et al. 1982). Slavin et al. (1982), who interviewed 116 long term paediatric survivors to assess their long term psychosocial adjustment found that patients who were informed and had a chance to discuss their diagnosis coped better than those who had their diagnosis shielded from them. Further, Vernick & Karon (1965) demonstrated the importance of creating an environment in which children with cancer feel safe to ask questions about their illness. They argued that children over the age of nine should be informed of the diagnosis. Binger and his colleagues (1969) agreed that children should be told of the diagnosis but stated that children aged four and above should be informed of their diagnosis. Researchers who favoured an open approach generally agreed that the greatest source of a child's anxiety came from being isolated when the parents tried to keep the diagnosis a secret and channeled most of their energy toward this end. Such channeling of parental energy was often futile, as these researchers discovered by interviewing the children that they were often aware of the seriousness of their own illness and some children even anticipated their own death (Spinetta, 1980) Accordingly, research conducted after 1980 appeared to advocate the need to tell children with cancer the truth about their illness. This change in approach may be related to the change in physicians' beliefs and attitudes that children who are of appropriate age should be informed of their diagnosis.

Spinetta, (1981) stated that health care professionals can best prepare to successfully discuss the diagnosis and prognosis of cancer with the child and the parents by understanding the parents philosophical beliefs regarding death, the child's age and level of development and the parents' coping strategies. Martinson, Su & Liang (1993) interviewed 25 parents (the exact number of fathers and mothers was not reported in the study) and reported that it was best that the whole family be told of the diagnosis, as this lessens the burden on the parents. Martinson et al. (1993) further stated that it would be ideal for the older child to be involved in the initial conference between the mothers father and physician to discuss issues regarding diagnosis, treatment plan and the prognosis of the disease. However, the issue of assessing the child's readiness in terms of their cognitive development and willingness to participate in such a conference was not addressed in the research. This issue is an important one to explore prior to the child's participation in such a conference in order to determine the appropriate breadth and depth of the disclosed information. Therefore, the maintenance of open communication channels among family members allows parents to better support their child.

Chelser & Barbarin (1987) conducted semi-structured interviews with 94 parents and concluded that the decision to share the diagnosis with others aside from members of the family relates to the individual parent's acceptance of the child's illness and the changes it has brought to their lives. Walsh-Burke (1992)

stated that mothers and fathers who choose to keep the child's own diagnosis of cancer a secret from the child are concerned about how others view the child with cancer as society often stigmatises those with such an illness. Therefore, to avoid social isolation from their friends and concerns that they may be ostracize by society, these parents may feel it best to keep their child's illness a secret (Chesler & Barbarin, 1987). As most of research on this subject has been conducted in the United States with Caucasian parents, very little is known about how parents from other cultures deal with this issue.

Impact Of Cancer Treatment On Parents

The second major dimension to emerge from the literature was the impact of cancer treatment on the parents. In the study by Bozeman et al.(1955), it was found that mothers of children with ALL experienced separation anxiety and this might be related to the dilemma created by the hope of a cure for their child and the possibility of losing the child permanently upon admission to hospital.

Faulkner, O'Keeffe & Peace (1994) argued that multimodal treatment protocols have contributed to the increased survival rate among children with cancer, but pain remains a major problem for these children and their parents. Miser & Miser (1989) stated that the pain experienced by the child is mainly related to the treatments involved rather than to the tumour, and much of the information previously available on pain in children has been associated with

procedural pain (Beyer & Levine, 1987; Broome & Lillis, 1989). With parents being encouraged to stay with their child during these painful invasive procedures, they can be of extreme stress to the parents (Mulhern, Fairclough, Smith & Douglas, 1992). It has been suggested by Pearse (1989) that very few fathers or mothers can tolerate seeing their children suffer during treatment. There are limited published studies in exploring parental experience when caring for a child with pain (Beyer & Levin, 1987; Ferrell, Rhiner, Shaprio & Dierkes, 1994; Ferrell, Rhiner, Shaprio & Strause, 1994). Beyer & Levin (1987) interviewed 10 mothers and reported that mothers' emotional reactions were heightened when the child underwent pain associated procedures for treatment for cancer. They further concluded that parents who witnessed this distress during their child's treatment may question the necessity for the procedure and may object to the treatment. Ferrall, Rhiner, Shapiro & Strause (1994) distributed the Family Pain Questionnaire and the Caregiver Burden Scale to 31 caregivers (30 parents and one grandmother) of children with cancer to assess their knowledge of and attitudes towards pain control and to measure their burden in caring for a child with pain. They concluded that it was extremely stressful for the parents to care for children who were in pain and rated emotional aspects of caregiving as providing the heaviest burden. These findings were supported by Chelser & Barbarin (1987) when they reported a sense of helplessness experienced by the parents while looking after their child who was in pain.

The issue of financial strain on the family resulting from the diagnosis of cancer in a child is another important issue that was reported in research studies. Financial difficulties facing these families were first documented by Lansky, Cairns, Clark, Lowman, Miller & Trueworthy (1979). 70 families with a child with cancer in Lansky et al's study were asked to complete a weekly log of nonmedical expenses and the researchers reported that parents of children with cancer endured income loss throughout their child's treatment span and 35 families reported a loss of more than 25% of the weekly family income. Frequent trips to the hospital also placed considerable stress on the financial status of these families. This finding was supported by another study by Lansky (1985). Lansky et al. (1979) and Lansky (1985) which studied the effects of non-medical costs on the family and concluded that increased costs occurred throughout the treatment, and a loss of steady income as a result of accompanying the child to the clinic placed considerable hardship on the family. Monaco (1983) stated that this financial drain contributed immensely to stress among parents of children with cancer. A study by Martinson et al. (1993) of 25 parents from mainland China discovered that these parents also faced financial hardships. However, unlike parents from the North American studies, the sources of their financial difficulties accumulated mainly from medical expenses. Non -medical costs were not looked into.

Aitken & Hathaway (1993) studied the effects of distance related stressors on the family. They found that 16 families in their study who lived over one hundred

miles from the treatment center used more funds for non-medical costs such as fuel, lodging, airfare and food . However, unlike in Lansky's (1985) study, parents in Aitken & Hathaway's study reported that those parents who lived further away from the treatment center missed less work in comparison to those who lived closer to the center and therefore endured less financial difficulties. This establishes that families of children with cancer may encounter financial difficulties during the course of their child's treatment.

Lansky, et al. (1978) utilized the state wide divorce rate as a gross indicator of marital functioning and concluded that parents did not become closer and that the divorce rate was comparable to that of the overall rate. Stehbens & Lascari (1974) argued that childhood cancer is associated with an increased divorce rate whereas Peck (1979) reported that the diagnosis of cancer in the child actually strengthened the marital bonds. Such discrepancies are perhaps related to the use of divorce rates, which are crude measures of marital relationships because marital problems do not always end in divorce (Koocher & O'Malley, 1981; Chelsea & Barbarin, 1987). Therefore, it is difficult to obtain a clear picture of whether having a child diagnosed with cancer in the family is responsible for an higher likelihood of divorce.

Sources Of Support For Parents

The third category involved the sources of support for parents with a child with cancer. Morrow, Carpenter & Hoagland (1984) investigated the role of social support in parental adjustment to childhood cancer. Morrow et al. conducted a cross - sectional study using 107 parents and found that the psychosocial adjustment of the parents correlated positively with the amount of support received from the spouse, relative, primary physician, or other parents having a child with cancer. Questionnaires were sent to parents, and 65 (61 %) of the respondents were mothers. All respondents rated their spouse as the most constant source of help and support followed by medical personnel (physicians and nurses), friends, parents in mutual support groups and neighbours. A study of the effectiveness of parent support by Williams (1992) demonstrated that parent-to parent support networks developed quickly in hospitals and that parents often sought emotional support from each other by sharing news of their child's status. In Morrow et al's study parents who were younger than thirty years old had more difficulty adjusting to the diagnosis with these parents reporting more adjustment problems in the areas of sexual relationships, relationships with extended family members and increased psychological distress. One possible explanation for this finding is that the relatively young age of these parents is a disadvantage as they are at a different developmental stage, have had less time to develop a support network and therefore have fewer resources.

The findings from the study by Morrow et al (1992) demonstrated that a potential source of support for parents of children with ALL is their religious faith. 40 (37%) of the respondents in Morrow et al's study stated that their spiritual beliefs were among the greatest sources of help during their child's illness. Although a personal faith or belief in God was seen by these parents as the most helpful support during the child's illness, the church itself played only a limited role in the parents' support system. Thus, religious beliefs may be a potential source of support for some parents with a child diagnosed with cancer. Only 7 (6%) of the parents in Morrow et al's study found traditional mental health professionals helpful but many stated that talking to a mental health professional might help with their family and marital difficulties, about which the authors did not elaborate. Another possible reason for such low utilization of the traditional mental health services may have been related to the stigma of seeing such professionals (Worden & Weisman, 1980). Interestingly, only 10 (15%) of 69 respondents in Morrow et al's study stated that the siblings might also benefit from receiving more support, but the types of support they felt the siblings needed was not specified.

Coping Strategies Of Parents Of Children With ALL

The fourth category that emerges from the literature review is the various coping strategies utilised by parents of children with cancer. Chesler and Barbarin (1986), who interviewed 74 parents (50 mothers and 24 fathers) extensively, found that all but one parent reported that they were coping well and 18 (24.3%) gave themselves excellent ratings. Parents reported that they coped by using information seeking, problem solving techniques, informal help seeking behaviours, maintenance of emotional balance, being optimistic, using denial accepting the situation and relying on religion. These problem solving techniques were reported by other studies with parents responding to the stress of childhood cancer by seeking information and understanding of the disease and its treatment (Friedman et al., 1963; Hamovitch, 1964; Hymovitch, 1976; Clark-Steffen, 1993). Futterman & Hoffman (1973) reported that some parents

> "use intellectual mastery to gain some sense of control, as though knowledge actually were power" (pp. 133).

Recent studies also support the importance of information seeking behaviours of parents of children diagnosed with cancer as a means to help them regain some control and cope with the disease (Kupst, Schulman, Honig, Maurer, Morgan & Fochtman, 1984; Moore et al, 1986). In view of the above findings, Kupst et al. conducted a longitudinal study in 1982, to study the effects of implementing a psychosocial intervention programme for families of children with leukaemia.

Their study demonstrates that the most important time for providing psychosocial support and interventions is at the time of the child's diagnosis. Moore et al. (1986) state that the majority of information is given to parents shortly after the diagnosis, which is the most stressful time for these parents. They caution that health care professionals should limit the amount of information given to the parents initially and suggest that information should be given on a continuous basis. They further suggest that the type of information given and the method of dissemination should be tailored to the learning needs of the parents and their child's condition.

Research has shown that parents can effectively use denial to cope with their child's diagnosis initially (Adams & Deveau, 1988). These researchers stated that by utilizing denial and refusing to accept the diagnosis the parents were reducing the impact of their child's diagnosis on their lives and allowing themselves to function. Adams & Deveau (1988) stated :

> "Parents who cope well tell us that they don't continually think about the disease and need 'time off '(pp.77).

Kagen-Goodheart (1997) suggested that the coping behaviours and strategies utilized by the parents of children with cancer vary according to the age of the child, the quality of their marital and family relationships and economic and financial factors. Other factors include the parents' previous experience with cancer, the adequacy of their support network and in particular the communication

patterns within the family and with the health care professionals (Futterman & Hoffman, 1973; Hymovitch, 1976; Moore et al., 1986; Chelser & Barbarin, 1987). Chelser & Barbarin (1987) interviewed 20 sets of parents whose children had just been diagnosed with cancer. The children were of different age groups and they found that parents had more difficulty in communicating the diagnosis to the adolescents than with the younger children. Share (1972) suggested that the younger children were possibly never told of their diagnosis.

It has been well documented that parents of children with cancer need support throughout the course of the illness and after treatment (Moore et al., 1986; Kazak & Nachman, 1991). Kazak & Nachman (1991) argued that the majority of support groups are available to children and their parents while they are in hospital and that little support is available after discharge. Williams (1992) utilized participant observation and in-depth interviews of 12 mothers and three fathers to obtain parents' views on support while their child was in hospital and at home. She concluded that the informal parent-to-parent networks developed quickly in the hospital and offered the most support during their child's hospitalization. The same study by Williams found that the most helpful coping strategies are for the parents to talk to each other and encourage one another during difficult times. Therefore, she suggested that nurses should be aware of the beneficial effects of such parent groups and that these relationships need to be monitored and further encouraged by health professionals.

Coping With The Uncertainty Of The Disease

Studies have shown that uncertainty regarding the disease and treatment is a major concern of parents of children with cancer (Bozeman et al., 1955; Koocher & O'Malley, 1981; Martinson et al., 1990; Clark-Steffen, 1993). With the diagnosis of cancer, parents become concerned with the problem of uncertainty. Even with advances in medical technology, there is no guarantee that their child will be cured. The term "Damocles syndrome" was used by Koocher & O'Malley in 1981 to describe the feelings of these parents.

Clark-Steffen (1993) studied the effect of uncertainty on 40 members of 7 families in which a child had been recently diagnosed with ALL by interviewing them using a semi-structured interview guideline over a time span of 3 months. The members of the families were interviewed at the time of the child's diagnosis (6 -13 days post diagnosis), at remission after the completion of induction therapy (5 - 12 weeks post diagnosis) and again 3 months after remission. The disease trajectory was used to guide the researcher as to when to interview the parents as the parents' response would be greatly influenced by the child's condition. Findings in this study indicated that families in the study stressed the importance of open communication between the family and the health care professionals as a major way of alleviating the fear of uncertainty throughout the course of the illness. Health care personnel are discouraged from giving the family any information until all the results from tests are known. However, data from Clark-

Steffen's (1993) study argues that families often imagined the worst possibilities and it is best to be honest and share with the families test results as soon as they are available in order to alleviate their concerns. This view is supported by Binger et al. (1969) who suggested that open communication in the form of an initial conference with all family members including the child should be encouraged. Brett & Davies (1988) who studied the effect of the uncertainty of ALL on families with a child 5 years into remission reported that parents and siblings continued to worry about the uncertainty of the illness and this in turn affected their lives and the way they treated the child.

Research studies involving Chinese Parents

The literature search only located two research studies into the experiences of Chinese parents having a child with cancer and both were conducted by Martinson together with colleagues from Taiwan and mainland China. The first study was conducted in Taiwan in 1981 and a similar study was repeated with a sample from mainland China in 1989. These two studies generated the only published articles on the experiences of parents with a child diagnosed with cancer in China (Wang & Martinson, 1982; Chen, Chao & Martinson, 1987; Martinson, 1982; Martinson & Martinson, 1988; Martinson, 1989; Martinson & Liang, 1992, Martinson Chang & Liang, 1993; Martinson, Su & Liang, 1993). Both of these studies were

conducted over a period of six months and involved one or both parents, siblings and grandparents of the affected child. Parents of children who were newly diagnosed with cancer (Group A) , those who were receiving treatment for cancer (Group B), those who relapsed (Group C) and those who had died from cancer (Group D) were all invited to participate in both studies (Martinson, 1982; Martinson et al. 1993). Data collection methods included the review of medical records, three general data forms and semi-structured interviews with the parents, the affected child, a sibling and grandparents. In this dissertation, the researcher would only comment on the experiences of the 25 parents in group A in both of these Chinese studies. The general data forms included the child's history prior to admission, the events during readmission to hospital and the summary of the child's outpatient visits (Martinson, 1982; Martinson et al. 1993). These forms were filled out by the nurses prior to interviewing the parents. 25 parents were interviewed for group A in both studies but the exact number of fathers and mothers being interviewed was not stated as Martinson and her colleagues only reported the total numbers of fathers and mothers interviewed for all four groups. Results from both studies show that there were more similarities than differences in the experiences of parents in Group A. All parents in both studies indicated that their spouse was their main source of support followed by the physicians when the child was first diagnosed, and parents reported no changes in their marital relationships (Martinson, 1982; Martinson et al. 1993). Seven families in the Taiwanese study reported having financial difficulties and had incurred heavy debt

in relation to the length of their child's treatment and eight fathers (33%) took time off to care for the child (Martinson, 1982). A similar number of families from mainland China also reported financial difficulties and several families (the number was not specified in the report) were concerned as to whether they had enough money to continue their child's treatment (Martinson et al. 1993). Parents in the Taiwanese study identified the distance from home to the treating hospital and the frequency of visits to the hospital out-patient clinic a major source of stress with no explanations given (Martinson, 1982). Many parents from mainland China also reported that the distance travelled to the hospital was stressful as they lived far away, and the children were left alone in the hospital while the parents returned to work (Martinson et al. 1993). 19 (75%) of the Taiwanese parents reported an increased use of folk religious practice after the diagnosis of their child's illness but such practices were not reported by parents from mainland China (Martinson & Martinson, 1988; Martinson et al. 1993). It is suggested that fathers and mothers respond differently to having a child with cancer (Larson, Wittrock & Sandgren, 1994), but this was not investigated by Martinson and her colleagues in the two Chinese studies. Chinese from Hong Kong are influenced by Western and Chinese cultures, therefore the experiences of Hong Kong Chinese parents with a child with ALL may differ from their counterparts in Taiwan and mainland China. With the lack of research involving fathers in western and eastern countries, it is important to involve the fathers in this study.

Summary of issues from literature review

From the literature review it is clear that the focus of research on parents' experiences with childhood cancer has been greatly influenced by the progress in medical technology in treating the disease. Advances in medical technology have influenced the approach to studying the families with a child diagnosed with cancer. Earlier literature focused on issues of death and dying, and on preparing the parents and the child for the child's imminent death. The focus of recent research has shifted to the emotional aspects of living with cancer and the main themes of coping with and adjusting to living with the disease. Many research studies have emphasized the issue of the uncertainty of living with cancer and its effects on the whole family. As long as childhood cancer is not a completely curable disease, it is unpredictable whether a child will die or be cured. Also in recent years, researchers have recognised the importance of exploring the experiences and impact of childhood cancer on fathers. Unfortunately, fathers of these children were not the focus of the early researchers, therefore their perceptions and feelings are virtually unknown.

Moreover, since many of the previous studies focused on describing parental responses to the child's illness, situational and personal characteristics of the parents were often not taken into account. The majority of studies to date involve parents from western countries, mainly the United States of America. Studies involving Chinese parents conducted by Martinson et al. only include parents from mainland

China and Taiwan. Findings from studies carried out in the States were different to those from studies carried out in Asia. There are differences in experiences across cultural groups as all groups assign different meanings to their experiences and these will shape their behaviour. Therefore, it is possible that the different cultural backgrounds of these parents may influence their experiences. In addition, issues relating to pain in children and how parents cope with seeing their child in pain have not been fully investigated.

Chapter 3

Methodology

Research Design

This was an exploratory study of experiences of Hong Kong Chinese parents of children with ALL. In order to achieve this the researcher chose a qualitative approach to research design to conduct this research, as there had been only two studies conducted with Chinese families and neither of these studies focused on the experiences of the fathers. In view of the above, little is known about the experiences of Hong Kong Chinese parents, in particular the fathers of children with ALL as previously discussed. Such a choice of design was supported by Brink (1989) who stated that exploratory designs using qualitative data collection methods would allow researchers to discover and uncover what is little known about a situation. Boyd (1990) further argues that a qualitative approach allows researchers to explore people's subjective feelings, thus emphasising a holistic view of human experience.

Talbot (1995) argued that qualitative research evolves from a discovery paradigm versus a verification paradigm and Miles & Huberman (1994) argue that qualitative data has been most effective in exploring new areas and leading to new discoveries. Cormack (1991) stated that people create meaning out of their experience through the interaction of internal and external realities. Therefore,

through the use of qualitative design the researcher explored Hong Kong Chinese parents' experiences of having a child with ALL.

The interview method has been found to be a valid approach to studying perception and experience in many qualitative studies (Clark-Steffen, 1993; Ferrell et al. 1994) This method allows the researcher to understand the other person's perspective as well as to learn about the feelings, thoughts and intentions of the subjects in a way that could not be achieved through observation. As argued by Patton (1987) this method allows the researcher to have a better understanding of the complex nature of perception and experience. The researcher employed a semi-structured interview format to explore information about the experiences of Chinese parents of a child with ALL by introducing the topic of concern and guiding the discussion by asking specific questions (Rubin & Rubin, 1995). Besides focussed questions, general questions were also incorporated into the semi-structured interview format, thus allowing the parents freedom to express their views.

Sampling

Parents with a child newly diagnosed with ALL were recruited from the paediatric oncological ward at a large teaching hospital located in the New Territories. Initially a total of 15 sets of parents were to be recruited but due to the low number of children diagnosed with ALL within the particular data collection time frame, a convenience sample of nine sets of parents were recruited using the selection criteria outlined below. Out of the nine sets of parents recruited, all mothers but only eight fathers agreed to participate in the study.

The criteria for selection were that the parents should be:

1. Older than 18 years of age.
2. Chinese who are permanent residents of Hong Kong and speak Cantonese as their first language.
3. Parents of a child diagnosed with ALL in the past month and aware of the child's diagnosis.
4. Currently suffering from no known mental health problem and not having been exposed to any other major stressful events in the past year.
5. Parents of a child who is not considered to be in any danger of dying within the next six months.

The sample was selected with the help of the consultant of the pediatric oncology unit using the previously stated selection criteria. All children newly diagnosed with ALL and their parents were screened by the consultant prior to contact with the researcher to ensure that the children were not at risk for the next six months, and that the parents had no current mental health problems. Parents with diagnosed current mental health problems were excluded from the study because it is not possible to ascertain within this study how this experience affects the parents' perception and experience of having a child with ALL. The requirement that all parents speak Cantonese as their first language is to ensure that information obtained from the parents would be consistent and also due to linguistic considerations to facilitate free expression of their experiences. Initial screening of the parents reflected the sensitive nature of the study, as parents who were considered distressed would not be referred to the researcher. The parents were asked initially by the consultant if they were willing to participate in the study prior to being introduced to the researcher.

Data Collection Method

The researcher chose interviewing as the main method for collecting data as it is acknowledged that the semi-structured interview is the most appropriate and important data collection tool for qualitative studies (Rubin & Rubin, 1995). The semi-structured interview schedule was generated through an extensive literature review and after consultation with experts in the area of pediatric oncology both

locally and overseas. The researcher's clinical experience working in the area was also used in developing the schedule.

The researcher incorporated both focussed and demographic data questions into the interview schedule to obtain in-depth information on the parents' experiences of having a child with ALL. The demographic data information were obtained by means of a demographic data sheet which included the age of the parents, their level of education, their occupation, their marital status, religious affiliation and monthly income. A genogram was incorporated into the interview schedule so that the composition of the child's family could be easily visualised. An example of a general question is asking the parents to describe their feelings when their child was first diagnosed with ALL. These questions aimed at eliciting the parents' experiences, including factors such as parents' perception of the child's illness, their experiences at the time of diagnosis and their perceptions of how the child's illness had affected them and the entire family. Other questions which related specifically to Chinese families in Hong Kong, such as the availability of the extended family were also incorporated into the interview guide. A similar interview schedule was used for the second interviews with the parents (See appendix II).

Data Collection Procedure

Previous research has shown that fathers and mothers may have different experiences in dealing with the diagnosis of their child's illness and may utilize different coping strategies in dealing with the child's illness (Townes et al., 1974; Barbarin, Hughes & Chesler, 1985; Larson et al., 1994). Therefore, the parents in this research were interviewed separately in order to obtain and to compare their individual views on having a child with ALL.

Prior to data collection, a briefing visit was arranged with the consultant of the paediatric oncology unit to explain the nature of the study and to seek his support and assistance. During the visit the same consultant agreed to give the researcher access to the hospital to conduct the study. Another visit was made to explain the purpose of the study to the nursing staff and to seek their support. This process was crucial to the success of the research as all initial parental interviews were conducted in the unit, as parents spent long hours at the hospital following the child's diagnosis.

One month after the child was diagnosed with ALL, the consultant approached the parents who met the selection criteria and asked if they would be interested in participating in a study about their experiences in having a child with ALL. If the parents agreed to take part in the study, the researcher was then

contacted by the consultant and an initial meeting with both parents was scheduled at a time that was convenient to them.

The data collection involved three specific stages. The initial meeting with each set of parents was generally scheduled at the hospital as the child was still receiving treatment at the time. At the first meeting the consultant introduced the researcher to the parents and then left the room. The researcher then proceeded to explain to the parents the nature and aims of the study and invited them to participate. The parents were informed that the interview would be audiotaped to facilitate the process of data collection and analysis.

The parents were interviewed twice using the disease trajectory of ALL to guide the timing of the interview schedule. The time for the initial interview was scheduled for at least four weeks after the child's confirmed diagnosis. From the literature review it was not possible to identify the best or most appropriate time to interview the parents. In previous studies, time of initial interview varied from three to four days post diagnosis (Kupst et al.,1982; Magni, Messina, De Leo, Mosconi & Carli,1983), to two months in some longitudinal studies (Morrow et al.,1987; Clark-Steffen,1994). In this study, the researcher chose to interview the parents at least one month after the diagnosis. This decision was based on the researcher's extensive work experience with these parents and the suggestion of the consultant of the paediatric oncology ward where the research was carried out. It

was considered important to give the parents time to come to terms with the reality of having a child diagnosed with ALL in order for the researcher to gain the maximum understanding of their experiences.

The scheduling of the second interview four months post diagnosis was based on the normal treatment regime for ALL, as by this time the child would have normally finished both the induction and consolidation therapies which often require frequent hospitalizations. After that time the child would be seen and followed up on by the oncologist in the out-patient department, as the treatment generally involves the oral administration of chemotherapeutic drugs and the occasional intrathecal drug administration. The interview was scheduled at that time to see if the parents' experience had changed from the time of diagnosis with the child's treatment being less intense. The parents were interviewed separately twice during the course of the study using the same interview schedule to see if there were any changes in the parents' experience over time. The interviews were conducted over a period of 18 months from March, 1994 to September, 1995.

The initial interview with each of the parents averaged one hour; the longest lasted one and a half hours and the shortest 45 minutes. Efforts were made to limit the interview to about an hour to avoid fatigue and to reduce the time parents spent away from their children. The second interview was relatively short in comparison to the initial one and averaged 30 minutes. Five sets of parents chose to have their

initial interviews conducted at the hospital and the remaining four sets of parents chose to be interviewed at their home. With the second interview, the same five sets of parents were interviewed at the hospital and the remainder were interviewed at home. The researcher was aware that interviewing the parents in different settings might have an effect on the depth of the data, as parents might be distressed at the hospital, whereas they might be more relaxed in their home environment, however it was important to respect the wishes of the parents.

Each parent was interviewed separately to ensure that the parent being interviewed could be totally free from the influence of their spouse in order to obtain their individual views on having a child with ALL. However, one set of parents requested to stay together for the initial interview conducting at their apartment and remained together for only part of the interview. Therefore, the researcher made note of this as this would affect the data obtained. The researcher was the only interviewer in the study. Field notes were kept of each interview to compliment the interview data, as both data obtained from the interview and data obtained from the field notes are important in interpreting the experiences of the parents. The process of taking field notes for each visit was time consuming but essential, as noting the parents' nonverbal behaviour and the interview setting was crucial. According to Munhall & Boyd (1993), the use of field notes helps in establishing goals for later interviews. Brief field notes were hand written on the spot, including notes on the physical setting, observations and the researcher's

feelings and reflections pertaining to the interview. (see Appendix VI for a sample of the field notes).

Transcription and translation of taped interviews was carried out by the researcher after each interview. The tapes were generally replayed immediately after the interview with the researcher listening to the content and to the tone of voice of the interviewee. Each taped interview was then transcribed and translated verbatim in its entirety by the researcher in the form of a written transcript (see Appendix III for sample interview transcript). All interjections including laughter and exclamations were included in the transcript. Non- verbal expressions of the parents such as facial expressions, gestures and pauses as indicated in the field notes were included in the transcript as well.

Ethical Considerations

Prior to carrying out the study, ethical approval was sought and obtained from the ethical committee of the Faculty of Medicine of the Chinese University. The consent form was translated into Chinese in order to facilitate the understanding of the parents. Written informed consent was secured from the parents prior to the interview, and the parents were reminded once again that the interview would be audiotaped. Permission to use the tape recorder was obtained verbally from each parent. The parents were advised that they could request the

tape recorder to be turned off at any time. Time was allocated for the parents to ask questions about the research after the briefing session but none of the parents asked any questions. The parents were also aware that they had access to the transcripts of the interviews if desired. The parents were fully informed and aware of the voluntary nature of the research, they were assured that their decision not to participate would not affect the care of their children in any way and that they could withdraw from the study at any time.

To ensure the confidentiality of the parents, they were given a code known only to the researcher which was used in the taping and transcription. Confidential information such as demographic data was securely stored by the researcher. Although direct quotes would be used in the report, the parents were assured that there would be no means of identifying them by the contribution they had made. In addition assurance was given that the parents' identity would not be exposed in the report. These and other necessary measures were taken to guarantee confidentiality.

The researcher also recognized the sensitivity of the subject under investigation and took extra precautions when interviewing the parents. The parent's expressions and their non-verbal behavior were observed closely by the researcher to detect any signs of fatigue and stress. The interviews would have been terminated as soon as these signs were present. However, none of the parents

interviewed showed any signs of fatigue or wish to terminate the interview and all data were collected without difficulty. The researcher was aware of the importance of separating the roles of researcher and nurse during the interview as the parents may have wanted to ask for advice. Extra care was taken by the researcher to take a passive position and avoid giving advice. This was to be accomplished by reminding the parents of the purpose of the interview in the event that advice was sought by the parents. However, no parents asked for advice during or after the interviews.

Pilot Study

A pilot study was conducted by the researcher prior to the collection of data for the main study. The research design and procedure for data collection were piloted using one set of parents to assess the feasibility and appropriateness of the interview schedule in obtaining the information needed to meet the aims and objectives of the study. Prior to the initial interview, the researcher met with both parents to explain the purposes of the study and to seek their participation. Parents were encouraged to ask questions about the study and confidentiality was guaranteed by the researcher. Verbal consent was obtained from both parents and the place and time for the initial interview were arranged. Both parents chose to be interviewed at the hospital in the late evening (20:00) when their child was ready for bed. Written consent was obtained from the parents prior to the actual

conduction of interview. The time span of the initial interview was carefully monitored to avoid parental fatigue and the time required for the mother and father in the pilot study was 60 minutes and 45 minutes respectively. At the end of the interview, the parents were asked to comment on the interview schedule and were asked if they had anything to add in order to get a better understanding of their experiences.

From the pilot study no problems with the interview schedule were identified in the two interviews and the parents were willing to disclose their demographic data without reservation. No further interview questions were provided by the parents. These tools were subsequently used in the main study. Since it was apparent from the pilot study that late evening (after 20:00) was a better time for interviewing the parents as the child was usually in bed, the ward environment was quieter and there was minimal disruption, this was incorporated into the main study. This time tended to fit into the schedule of the parents as well, as the father generally came to the hospital to visit the child after work. The second interviews with these parents were conducted at their residence without any problems.

Data Analysis

The data analysis process started early in the data collection and continued while the data collection was ongoing. Miles & Huberman (1994) recommend early analysis as it provides the researcher with opportunities to improve strategies for collecting data, and makes the process of final analysis less overwhelming. After the interview, the hand written field notes were typed and information such as the general facial expressions of the parents during the interview, interruptions during the interview such as phone calls were added to the transcript.

There is no single method for conducting the process of analysis of qualitative research data and various techniques have been described by different researchers (Morse, 1991; Munhall & Boyd, 1994; Miles & Huberman, 1994). The researcher chose to analyse the data for this study using the matrix system described by Miles and Huberman (1994).

The matrix system described by Miles & Huberman (1994) was used to display and analyse the research data. Transcripts from interviews with the mothers were analysed together and separately from those of the fathers. Each matrix consisted of rows and columns, the code of each parent was entered in each row and the response to each of the questions was entered into the column. Using the interview schedule, the response to each of the questions from the mothers was read at least three times and was then written in the appropriate column. This was

done after the researcher had reviewed passages within the context of the whole transcript with the aim of identifying subcategories for each major category. Each question from the interview schedule was analyzed and subcategories identified in the data were written in columns and the code for each parent was recorded in each row. Two matrices were created, one for the mothers and one for the fathers. The matrix for the mother had nine rows corresponding to the number of mothers participating in the study, and there were only eight rows for the matrix for the fathers as only eight fathers participated in the study. There were initially an average of 22 and 15 columns in the matrix for the mothers and fathers which corresponded to the questions asked of the parents. The categories from the questions were collapsed into subcategories and placed into the appropriate major category. (See Appendix V for sample of matrices for mothers and fathers).

Each couple was matched on the matrices so that the data from the mother and father of the same child could be compared, as father A and mother A would occupy the same row in their corresponding matrices. Therefore, the use of matrices facilitated the comparison of data from the couple and allowed the researcher to compare the views of the mothers and the fathers easily. Responses from mothers and fathers over the two time periods could also be compared. Therefore, matrices created from the two different interviews for each parent facilitated comparison of the mothers' data, the fathers' data and the couples' data.

Validation of subcategories developed from the major was done by asking two mothers who are bilingual, speaking both Chinese and English to read through their own transcripts, and to write down the categories and subcategories that emerged from the transcripts. The categories generated by the mothers were compared to those of the researcher and a high level of agreement was achieved. This method has been suggested by Burnard (1991) as an alternative way to validate categories and the findings.

A code was assigned to each of the parents and stored in a data file which facilitated easy identification of the transcript. Each set of parents was assigned to the same letter from the start according to the time they were interviewed . Therefore, the first set of parents were assigned the letter A, the second set letter B and so forth , in order to distinguish between the transcripts of the fathers and mothers, the letters F and M were used to denote father and mother respectively. Therefore, AF would be used to identify the father's transcript from the first couple and the mother's transcript would be designated AM.

Issues of Reliability and Validity

The value of scientific research is partially dependent on the ability of researchers to demonstrate the rigor of the methodology as well as the findings, and a frequent concern regarding qualitative research findings has related to the question of validity and reliability (Goetz & Le Compte, 1984). Therefore, both reliability and validity are important issues that need to be carefully addressed if research is to be of any value. Reliability in qualitative research is concerned with the consistency, stability, and repeatability of the informant's account as well as the researcher's ability to collect and record information accurately (Brink, 1991). Brink (1991) argued that the term "measurement" in qualitative research referred to a series of decisions made by the researcher about data collection to improve credibility, dependability and transferability and to address the issues of reliability and validity. Thus, the decisions made by the researchers on how to collect data most relevant to the aims of the study play a role in establishing the reliability and validity of a qualitative study (Brink, 1991).

Validity

Validity refers to the gaining of knowledge and understanding of the true nature of the research topic (Leininger, 1985) and to measure what is intended (MacKenzie, 1994). The researcher attempted to ensure the content validity of the interview schedule as it was designed by the researcher specifically to study Chinese parents in Hong Kong after consultation with nurse experts overseas and

locally and following an extensive literature review. The interview schedule was translated into Chinese by a nurse working in the paediatric unit and translated back into English by another nurse, both of whom were bilingual. The final version used in the research was agreed upon by the researcher and the two nurses. The researcher was aware of factors that may have threatened the validity of the interview method of data collection, including responses that reflect social desirability and a typical response set (Brink, 1991). These are sources for constant error which threaten the validity of the study. An example of constant error would be if fathers in the study informed the researcher during the second interview that they had not been telling the truth and that they had been saying things that were expected of them. The researcher therefore made an extra effort to inform the parents that there was no right or wrong answer to the questions, and the parents were assured that their responses would not in any way affect the treatment of their child. The researcher tried to ensure that the parents would share their true feelings by reminding the parents that the researcher had no formal association with the practice in the unit. In addition the parents were assured that professionals looking after their child would not have access to the tapes. Therefore, validity is enhanced through the establishment of a close relationship between the researcher and the informants.

In addition, Lincoln & Guba (1985) suggest the process of prolonged engagement can improve the validity of the data when enough time is allowed for

data collection and clarification of data. The researcher utilized this method to increase the validity of the data by clarifying the data with the parents during the second interview. The researcher was aware of conditions that threatened the validity of the study. In order to understand the experience from the parent's perspective, the researcher viewed the phenomena under study without any preconceived ideas or assumptions. Beck (1993) utilised the term "bracketing" to describe the suspension of the researcher's beliefs regarding the topic under study. Thus, the researcher attempted to put aside her own thoughts, stereotypes and assumptions which could have prevented her from being open and receptive.

The scheduled meeting between the researcher and the parents prior to the first interview helped to establish a rapport between the parents and the researcher. It was hoped that the scheduled meeting would provide the parents with the opportunity to ask questions about the research, and give them time to decide on whether or not to participate in the study. These procedures aimed to facilitate the parents' willingness to share with the researcher their true experiences of having a child with ALL thus increasing the validity of the study.

Reliability

Reliability is concerned with maintaining the consistency and accuracy of the data collected and to reduce random error (Mackenzie, 1994). An example of random error in the study was related to what was happening in the immediate environment while the interviews were conducted. Reliability was established in the collection of interview data by using a tape recorder to ensure the accuracy of the data and all the interviews were conducted by the researcher. Reliability during data analysis was ensured by the researcher transcribing the tape as soon as possible after the interview. The researcher listened to the tape a few times before and after transcription in order to increase the reliability of the study. The researcher was fully aware of the potential for errors attributable to the researcher's tendency to selectively take note of certain data and ignore other data. To reduce bias, the researcher asked two mothers to review their own literal transcriptions to verify that the consistency of the interpretation and that the categorization of content were accurate (Brink, 1991). This was to ensure that the researcher's interpretations of what the parents had said was accurate. As parents were interviewed twice, any misconceptions or cloudy issues could be clarified at the next meeting. These verification sessions thus clarified the content and the terminology used in the verbatim. The depth of the data could thereby be improved and the content is considered both valid and reliable due to the repeated interviews (Brink, 1991).

In order to avoid researcher bias, one randomly chosen taped interview was transcribed and translated by another registered nurse who has experience in doing qualitative research. This aimed at establishing the accuracy of the transcription and translation of taped interviews. The level of agreement between the two transcripts was high and no adjustments were made. This process further increased the reliability of the data collected.

Chapter 4

Results and Discussion

Introduction

As described in the previous chapter, the results of the study were acquired using the matrix framework described by Miles and Huberman (1994). Descriptive statistics were used to analyse the parents' demographic data. Major categories from the mothers and fathers are analysed and presented separately so that they can be read and interpreted independently. Sandelowski (1995) argued that results and interpretation of data should be presented together in complete qualitative research reports. The author has therefore chosen to present the results and discussion of the findings together using illustrated verbatim examples from the interviews in this chapter to facilitate easy reading and comprehension.

This chapter is divided into five sections. The first section describes the demographic data and the major characteristics of the parents. The second section describes categories and subcategories identified in the data obtained from the mothers and the third section includes categories subcategories identified in the data obtained from the fathers. The fourth section includes a comparison of the subcategories found in the data from the mothers and fathers and any changes in their experiences which emerged in the second interview. The last section includes

the differences between the initial and second parental interviews and a summary of the findings.

(I). Parents' Profile

Demographic Characteristics Of The Parents

The demographic characteristics of the parents are shown in Table 1. The results were drawn from the demographic sheet which the parents were requested to fill out prior to the first interview. A total of nine mothers and eight fathers participated in the main study, as one father who initially agreed to participate withdrew before the first interview.

All informants were married, the number of years the informants had been married ranged from two to twenty four years with a mean of 11 years. Two of the nine informants lived in public housing estates, four owned their own apartments, two rented their accommodation and one stayed in Government quarters for married civil servants. None of these parents reported having any affiliation with any organised religious group.

Table 1: Age and educational levels of mothers and fathers

Demographics of the parents	**Mothers (N=9)**	**Fathers (N=8)**
Mean age	36	38
Education Level		
-Primary school	2	3
-Secondary school	7	4
-Tertiary		1

Table 2: Occupation and mean income for mothers and fathers

Occupation	Mother	Father
Driver		3
Policeman		1
Hairdresser	1	1
Insurance agent	1	1
Housewife	4	
Clerk	2	
Kitchen helper	1	
Businessman		2
Mean monthly income	$8,800	$24,000

Table 3: Number of children per family and age of affected child

Family	No.of children	Age of the affected child	Gender of the affected child
A	4	3	Male
B	1	2	Female
C	4	14	Male
D	2	6	Female
E	2	13	Male
F	2	2	Female
G	2	5	Male
H	1	11 months	Female
I	4	9 months	Male

Table 2 demonstrates that informants from a range of socio-economic groups were included in the study. Three of the fathers were semi-skilled workers, three were skilled workers and two were professionals. The average household income ranged from a low of $9,000 to a high of $65,000. It appeared that the majority of the parents interviewed were in the higher income bracket. This was supported by the data for the combined household income which showed that only three of the families' combined income was less than $12,000. Only 50% of the mothers were in full time employment at the time the child was diagnosed.

The main focus of the parents' interview data was on the parents' experience of having a child with ALL as previously described in the methodology. The following major categories corresponded to the questions in the interview guideline and subcategories were developed from the data from the first interview with the mothers.

(II). Major categories corresponding to interviews with the mothers

Five major categories were developed from the questions asked of the mothers and these were:

Initial reactions to the child's confirmed diagnosis of ALL

Sources of support for the mothers

Disclosure of child's diagnosis

Uncertainty of child's future and illness

Changes in family routine

Questions were directed to all mothers, with some voicing more concerns than others within certain categories. Each of the major categories will be discussed in the following section.

Initial reactions to the child's confirmed diagnosis of ALL

The mothers were asked about their initial reactions when they found out their child had ALL. Within this first major category three subcategories were identified and these were:

Unpreparedness for the child's diagnosis

Suddenness of the child's diagnosis

Physical and psychological reactions to the child's diagnosis

Unpreparedness for the child's diagnosis

During the first interview, all the mothers revealed that they had never considered the possibility that their child's symptoms represented such a serious illness. Although they had suspected that something was wrong, seven of the mothers had thought that the child was coming down with a stomach flu or cold and the others thought that the child had some minor chest infection. As one mother commented:

> "He had diarrhea for two to three weeks and we brought him to see the doctor. I thought it was a stomach flu and never thought it was so serious..."(AM: R2).

In three cases, the mothers were further reassured of their interpretation that their children were not seriously ill by private physicians. The mothers' attempts to explain the children's' symptoms were similar to those reported in a study by Martinson & Cohen (1989) in which the mothers also attributed the child's conditions to some minor childhood ailments such as the common cold or flu. Other possible reasons for the mothers' interpretation of the diagnosis being less serious were that all the children had shown similar symptoms previously and had recovered without major complications. In addition, the literature suggests that the onset of leukaemia is insidious in many cases, the nonspecificity and vagueness of the signs and symptoms produce further ambiguity prior to the diagnosis (Cohen, 1995). Thus, the mothers' unpreparedness to find out their child's diagnosis prompted them to interpret the child's symptoms using illnesses that were familiar to them. The mothers' reactions may also be explained by the use of denial and hope that their child's condition was not serious. Literature review supported the use of such defense mechanisms in helping mothers to normalise their daily routines thus allowing them to go on with their work (Martinson & Cohen, 1989; Martinson et al. 1993).

Suddenness of the Diagnosis

Due to the suddenness of the child's diagnosis, all but two mothers stated that they were not prepared to hear that their child had cancer. In one of these cases, the child was admitted to a private hospital for four days with no definitive

diagnosis prior to the confirmed diagnosis of ALL. This mother stated that she felt relieved as finally treatment could be implemented and she no longer had to worry about what was wrong with the child. This is illustrated by her saying:

> "I was relieved in a way that she was had ALL, I thought we had wasted enough time already. Finally, she could start receiving treatment..." (BM:R6).

In the other case, the possible diagnosis of cancer had been suggested by the private physician. Therefore this mother had more time to come to terms with the situation. This is illustrated by her saying:

> "He had his blood tests done at a private laboratory. The doctor said that there was something wrong with his blood..... When Dr. L told me the diagnosis, I was fairly calm..... " (CM:R8).

Although the mothers were told of the confirmed diagnosis of ALL by the consultant and the medical team of the pediatric oncological ward at hospital A, six children were initially admitted to another hospital for investigation of initial complaints and later referred to hospital A when leukaemia was suspected. Eight out of nine mothers were informed that their child had a blood disorder before being transferred to the special unit, but when the diagnosis was confirmed, they claimed the suddenness of the event was still upsetting for them.

Hearing the child's diagnosis might have been less traumatic for the majority of the mothers if the physicians from the other hospitals had been open with the mothers and the diagnosis of ALL had been shared when ALL was suspected. Open discussion of the child's confirmed diagnosis with the parents in order to reduce mothers' anxiety was supported by research studies (Binger et al. 1969; Martinson et al. 1993).

Physical and psychological reactions to the child's diagnosis

Another important subcategory involved mothers in this study describing their feelings of exhaustion one week after the child's hospitalization as they all stayed overnight with their child the first week. However, the mothers' decision to stay overnight with the child during the entire hospitalisation appeared to depend on the age of the child and the amount of physical support received by the mothers. Two children under one were accompanied by their mothers throughout their entire hospitalization, and the mothers only agreed to leave when their husbands came to relieve them. Five mothers whose children were between two and six years of age received help either from the extended family or live in helpers after the initial week. Two mothers whose children were teenagers did not stay with their children beyond the first week of hospitalization.

Although all the mothers stated that they felt exhausted, those with children who were teenagers and those who had help from extended family members and

live in helpers reported feeling less tired and physically stressed. This finding perhaps pertains only to Hong Kong where families from the higher socioeconomic groups often have live in helpers. Therefore all except two mothers whose children were under one year old reported that their exhaustion decreased after the initial week. Only one mother reported having severe sleep disturbances. This same mother also had a history of hyperthyroidism and was experiencing an exacerbation at the time of the child's diagnosis.

Psychological reactions experienced by mothers upon hearing their child's cancer diagnosis ranged from shock, being overwhelmed, disbelief, feeling frightened and confused, feeling hopeless and helpless, uncontrollable grief and hostility toward the physician to philosophical acceptance. Of these reactions all mothers reported that they were frightened, overwhelmed and cried uncontrollably. One mother stated :

> "When I was told of her diagnosis, I cried and cried and couldn't stop. I was afraid that I might lose her" (DM:R4).

Only one mother reported that she experienced a long period of guilt in an attempt to explain the child's illness saying once she had had time to reflect on the situation:

> "I am sure the reason for him getting this dreadful disease is that I had a chest x -ray when I was carrying him..... I can't help but feel guilty" (AM : R10).

This mother's assumed responsibility for her child's illness was also noted in a study by Bozeman et al. (1955) in which a majority of mothers in the study exhibited similar feelings. Other studies have shown that once the diagnosis of ALL is made, parents often blame themselves for neglecting the early manifestations of the disease and worry that delay in seeking medical advice jeopardized the child's chance for survival (Friedman et al. 1963; Martinson et al. 1989). Interestingly, feelings of self blame for delaying the diagnosis of the child's illness were not evident in this study, as all mothers stated that they had sought medical advice from a private practitioner at the onset of their child's symptoms. Two mothers voiced their concerns about not paying enough attention to the dietary intake of their children. These mothers however did not blame themselves, but attributed their child's illness to a lack of caring by the domestic helper as these mothers worked full time. This finding may be unique to Hong Kong as domestic helpers also live with the family and in some cases these hired helpers actually replaced the mothers in caring for the children (Wu, 1995). These findings were different to a study by Chen et al. (1987) with Taiwanese parents, in which the mothers felt that their negligence during pregnancy and their ignorance about their child's nutritional intake were responsible for the child's condition. The difference in findings may be explained by the use of avoidance and blame to resolve higher levels of psychological distress in Hong Kong residents (Phillips & Pearson, 1996).

When the diagnosis was confirmed, all but one of the mothers stated that they were very scared, were in a state of shock and cried when they were told of the

diagnosis even though the term "cancer" was not used by the physicians. In addition to feeling scared two mothers reported that they were worried and felt hopeless and helpless. One described her feelings saying :

> "I was in shock and cried when Dr. L told me his diagnosis even though he did not use the term cancer. I knew right away that it was cancer" (FM: R12).

It is interesting that none of the physicians in this study used the term cancer in explaining the diagnosis to the parents which may be explained by the stigma still attached to cancer (Walsh-Burke, 1992). Indeed the mothers in this study reported that they were all scared as they had some knowledge about the disease of the "white blood cells" as the disease had received much attention from the media at the time. The physicians' choice to not use the term cancer was perhaps detrimental as this further reinforced the mothers' belief that cancer is a taboo subject and their child's diagnosis should be kept a secret. The finding that the mothers were all scared of the term cancer is similar to a study by Martinson et al. (1982) in which the majority of the Taiwanese families in the study identified cancer as the most threatening and frightening illness.

The initial reactions of the mothers reported in this study is consistent with the findings of other studies by Bozeman et al. (1955), Binger et al.(1969), Chen et al. (1982) and Martinson et al. (1993). Data suggest that parents from North America, Taiwan, mainland China and Hong Kong, although from different

cultural backgrounds, all react to the diagnosis of their child's life-threatening illness in a similar way. One reason for this may be that some parents who were interviewed in the Taiwanese and mainland Chinese studies might have been subjected to differing degrees of Westernisation (Phillips & Pearson, 1996) and that these studies were conducted in the capital cities of the two countries (Chen et al. 1982; Martinson et al. 1993). Therefore, mothers, regardless of their cultural background may react to a life-threatening illness in a similar manner.

Sources Of Support For The Mothers

The second major category identified was that of sources of support for the mothers. From the data two subcategories were identified and these were:

The mothers' main source of support

Other sources of support for the mothers

The Mothers' Main Source Of Support

All but two mothers in this study stated that their spouse was their main source of support because they comforted them and reassured them that the child would be all right.

> "My husband comforted me and said that we would get through this together and that our son was being looked after by the best doctors in this field...."(FM:R 20).

The Hong Kong Chinese family is now in a state of transition from the traditional extended unit to the isolated nuclear unit with the nuclear family now becoming the norm (Tseng & Wu, 1985). In the case of the nuclear families, husbands and wives make up the main support framework for each other as less support is available to the couple from the extended family (Wu, 1995). Therefore, they turn to each other for help and comfort especially in times of stress (Martinson et al. 1993). This finding is consistent with the findings in studies by Chen et al. (1987) and Martinson et al. (1993) in which Chinese parents turned to each other for support. This finding is also similar to a study by Morrow et al. (1984) of Caucasian parents in which the spouse was considered the most important source of support for all parents. Therefore, parents of different ethnic backgrounds appear to turn to their spouses for support in times of need.

The remaining two mothers in the study stated that they received their main support from other members of the extended family. One mother said she received emotional support from her mother who lived in mainland China. This mother was having difficulty with her husband at the time and therefore chose to seek support from her mother. She commented:

> "My mother has supported me so much throughout this ordeal. I owe her so much and don't know how I can repay her. I was having some arguments with my husband at the time....." (IM:R26).

This further illustrated that these mothers would seek support preferably from their spouse followed by members of the extended family who are still considered family members. Such relationships are strictly dictated according to role and duty (Yang, 1993). Therefore, traditional extended family might have been called upon to provide material and psychological security for these two mothers.

Other Sources Of Support For The Mothers

Data from this study indicated that besides members of the nuclear and extended families, the majority of the mothers had their own support system which consisted of medical professionals, co-workers, friends, other mothers on the unit and the use of religious rituals. It has been well documented in the literature that families of cancer patients experience considerable stress (Moore et al. 1986; Martinson et al. 1990). Social support has been suggested as a useful method of dealing with the effects of stress (Morrow et al. 1984). All the mothers stated that the consultant and all but one mother stated that other physicians offered verbal support to them and that this was helpful. The consultant who was considered helpful by all the mothers has perhaps developed a way of informing the parents of the diagnosis without unduly upsetting them. One mother commented:

> "Dr. L comforted me, said that his condition was stable and that the doctors would do everything to help him....(AM:R20).

Nurses were cited by three mothers as being supportive. It is interesting to note that all of these nurses were from the referring hospital. This might be explained by these nurses being described as "older" by the mothers, thus having previous experience in working with mothers who were under stress and being able to provide some information about the child's condition and prognosis. One mother commented:

> "The nurses were very nice and told me not to cry, they said that she had a good chance to survive because of her age....." (FM:R18).

Also one mother stated that these nurses were more willing to listen because they do not have to encounter such stressful situations often:

> "The nurses were very patient and explained to me the need to transfer her right away to the other hospital and reassured me..." (BM:R20).

However, two mothers stated that the nurses offered no assistance or support to them and were resentful towards many of the nurses working in the referred hospital. One mother stated:

> "None of the nurses offered any help, I didn't want to ask because they were not very helpful from the beginning. They all pretend to be so busy.." (CM:R23).

The finding that nurses were not supportive had not been reported in other studies. This might be related to a lack social and interpersonal skills dealing with the mothers or that they were not comfortable in discussing sensitive issues relating to the

condition of the child (Coyne, 1995). Nurses may also avoided getting too emotionally involved to prevent themselves from identifying with the mothers.

Disclosure Of Child's Diagnosis

The third category identified was whether mothers disclosed their child's diagnosis to others. Three subcategories were included in this category and these were:

Disclosure of the child's diagnosis to the child

Disclosure of the child's diagnosis to members of the immediate and extended family

Disclosure of the child's diagnosis to non family members

Disclosure Of The Child's Diagnosis To The Child

When the mothers were asked if the child was aware of the diagnosis, they all stated that they had not told the child immediately on confirmation of the diagnosis. One explanation for this may be that these mothers were still in shock and having to cope with their own feelings, and therefore did not think that disclosing the diagnosis to the child was a priority at the time. Four mothers did not tell the child the diagnosis at all because they were too young, all being under the age of three. This is illustrated by the comment:

> "He is too young to understand what is happening to him. There is really no point in telling him the truth" (JM:R8).

Mothers with children whose age ranged from seven to 14 years stated that it was difficult to tell them the real diagnosis and they were reluctant to do so at the beginning. This may be related to the mothers' desire to protect the child or their inability to answer the child's questions about their prognosis (Canam, 1987). The children who were between the age of four and six were later told that they were not well when the mothers thought that they needed to tell the children something because of the frequent visits to the hospital. The mother of one child age five stated:

> "I told him that he had some worms inside him and that he would need to take medicine for a very long time to get rid of the worms...." (GM:R9).

The mothers of the two teenagers in the study did not tell them the diagnosis themselves. The two children learned of their diagnosis from different sources. One of the mothers stated that her child overheard his diagnosis when medical students discussed his case with other physicians. This mother was upset and stated that the doctor in charge should have stopped the discussion as it was inappropriate at the time. She commented :

> "The doctors and the medical students were seeing the children and he overheard them discussing his case and they used the term blood cancer. The doctor in charge should have known better....." (DM:R10).

According to the mother of the other teenager he just knew without being told by anyone as he had seen a documentary about ALL on television one evening. This mother said:

> "There was a documentary about leukaemia on TVB one evening. He watched it and cried that evening because he thought he was going to die ....." (CM:R12)

The mothers' decision in this study to not tell the truth or not tell the whole truth is related to the young age of the affected children. Mothers are also more inclined to protect younger children from harm and they believe that the children are too young to benefit from the knowledge. These findings were similar to those of studies conducted by Martinson et al. (1982) with Taiwanese parents in which older children learned about their diagnosis by overhearing others and younger children were told only the partial truth.

Disclosure Of Child's Diagnosis To Members Of Immediate And Extended Families

After the child's diagnosis was confirmed, all but two mothers reported that members of immediate and extended families were told. Reasons given for not telling were that one paternal grandmother's physical condition was not good and that she resided in Canada. This particular mother therefore thought that it was best not to tell the grandmother the truth, although she was aware that the child was

ill. Three mothers with older children who chose to tell the siblings the diagnosis reported no difficulty. The reason given was that these children were over 16 and were aware of the seriousness of the illness. The mothers chose to inform them so that they could help with the housework. This is illustrated by one mother saying:

> "We have no secrets in the family, we told them right away after we found out..... They are old enough and can understand". (AM:R12).

Mothers with other young children aged four and under all chose not to tell the truth because they did not think the children would comprehend the situation. This finding is similar to a study by Martinson et al. (1993). Interestingly, all mothers told members of the extended families with whom they had a good relationship. The reason for this may be that mothers were more inclined to tell family members who could support them and were able to help when necessary. Therefore, the importance of extended families as supportive social networks was emphasised by these mothers and the fact that relationships between members persist long after they get married and move away (Gabrenya & Hwang, 1996).

Disclosure Of Child's Diagnosis To Non-Family Members

Mothers working full time at the time of the child's diagnosis disclosed the child's diagnosis to their co-workers without difficulty. These mothers needed to tell their supervisors the truth in order to take time off from work and they could perhaps obtain support from their colleagues if they had a good rapport with them. One mother commented:

> "I needed to tell my supervisor at work because I had to take so much time off..... It was not difficult to tell others" (BM: R16).

These mothers had worked in the same work place for an average of six years and stated that they had no difficulty in disclosing the child's diagnosis to their co-workers. Thus, these mothers received support from colleagues at work forming a rich network of "guanxi" which is unique to the Chinese culture (Gabrenya & Hwang, 1996 pp. 311).

All but two mothers did not tell their friends. Reasons given included a desire not to alarm others, to not burden people because they were busy, that people may be scared if they found out that the child had cancer and that friends could not help with the situation. These mothers specifically instructed the siblings not to tell their school mates about the child's condition. Stigma concerning cancer is still prevalent in Hong Kong as reported by one mother and is partly responsible for the mothers' decision to not tell others about the child's diagnosis for fear that the affected child and the siblings may be discriminated against.

> "I specifically instructed all my children not to tell anyone about his condition, I do not want the whole world to know, there is no need for that .....".(AM:R13).

One mother who is a full time homemaker and had very few friends stated that she did not tell her neighbours of 10 years about the child's diagnosis. This mother originated from mainland China and stated that she had never felt comfortable in Hong Kong. She commented:

> "I did not want to tell any of my neighbours whom I have known for 10 years, they often gossip..... " (IM:R8).

This finding of reluctance to share the child's diagnosis with the neighbours for fear that they would discuss the child's condition among themselves was different from a study by Martinson et al. (1989) in which the parents were willing to openly discuss the child's condition with the neighbours. This particular mother stated that her main support came from her mother and she had no friends whom she could trust.

Uncertainty Brought On By The Illness

The fourth category was the uncertainty brought on by the illness and three subcategories were identified:

Waiting for confirmation of diagnosis

Uncertainty about the success of treatment

Uncertainty about the child's future

Waiting For Confirmation Of Diagnosis

All the mothers related that their experience of waiting to hear the diagnosis or receive the results confirming the diagnosis was extremely distressing. The reason may be that they were all scared of cancer and believed that the disease is universally fatal. Such experiences were worse for three mothers in particular as illustrated by one mother's comment:

> "The doctor told me he may have had a form of juvenile arthritis and that he needed to rule out other possibilities, so the doctors ordered more tests. Waiting and not knowing is the worse experience.." (EM:R39).

Therefore, mothers who were reassured that their child had a less frightening disease initially experienced more difficulty during the waiting period because they had to speculate their child's diagnosis and had a problem in trusting the doctors' final diagnosis.

These findings are consistent with those of studies conducted in the United States, in Taiwan and mainland China (Clark-Steffen, 1993; Chen et al. 1987; Martinson et al. 1993). Uncertainty surrounding the diagnosis created a sense of urgency for the mothers and they were eager to receive the confirmed diagnosis. Those mothers whose children's' diagnosis had been suggested by another hospital

prior to transfer to hospital A stated that they were hoping that the diagnosis of ALL was inaccurate. Thus it appears that, the stress of the waiting period was somewhat eased by a sense of hope that the doctors could have made a mistake in the interpretation of the blood results.

Two mothers experienced more stress as diagnosis of the child's illness was delayed because of unavailability of medical and laboratory staff to carry out the necessary diagnostic tests for confirmation of ALL.

Uncertainty About The Success Of Treatment

The mothers' uncertainty did not cease after the child's diagnosis of ALL had been confirmed. Uncertainty remained and two mothers questioned the efficacy of the treatment regimen, and whether the drugs were sufficient to attain a remission. They also experienced fear of recurrence. This is illustrated by one mother saying:

> "I am not sure if he is responding to the drugs because he did not have any of the side effects that the doctors said he would experience....."
> (EM:R56)

The mothers' fear of uncertainty at this stage is related to the improved prognosis and lengthened survival rate of childhood cancers. The parents' experience has been described as "living in limbo" (Koocher & O'Malley, 1981). One mother expressed her fear thus:

> "He is like a walking time bomb and we don't know when he will explode" (FM:R50)

One possible reason that this mother expressed more fear was that her father-in-law died of cancer four years ago at the same hospital. She stated that relapse is possible even when the child is undergoing treatment.

All mothers said they coped with uncertainty by taking the one day at a time approach and trying not to plan or think about the future too much. This is consistent with studies by Chen et al. (1987), Martinson et al. (1993), Brown (1989) and Clark-Steffen (1993). Research studies showed that parents from different cultures may in fact utilise similar coping mechanisms when having a child diagnosed with cancer.

Uncertainty About The Child's Future

Only one mother in the study expressed concern about the child's future, the rest stated that they would take a wait and see approach. Mothers whose children were of school age chose to take the children out of school as suggested by the physician during the initial treatment. One mother commented:

> "Well, I never think ahead too much and just take one day at a time. It is out of my control and I just do what the doctors tell me." (AM:R50).

Data such as this suggests that mothers in this study were eager to relinquish control of their children to the physicians by listening to the physicians' suggestions. Reasons for this may be that physicians are trusted by the mothers, the belief that "doctors know best" is common among these mothers and that it may be a relief that their child is actually under the care of someone who is more knowledgeable than themselves. This finding is similar to a study by Martinson & Cohen, (1987).

One mother expressed more concern about the child's siblings, she commented:

> "I worry about his younger brother's future. The parents are not going to live forever and I don't want him to be a burden to his brother...." (DM:R46).

This finding is not reported in other studies and may be related to family relations and the socialization of Chinese children with an emphasis on a strong sense of sentiment for the family (Yang, 1993). The tradition of Confucianism and its influence on the family are still well established in the Hong Kong Chinese family (Anderson, 1992). In this family the mother stated that she expected the sibling to care for the affected child even though it was not fair.

Changes in the family routine

The last major category was that of changes in the family routine following the child's diagnosis. Only one subcategory needed to normalise family life was identified.

Needed To Normalise Family Life

All the mothers agreed that their family life had been affected since the diagnosis of the child's cancer, with some claiming more effects than others. This is illustrated by one mother saying:

> "The whole family has been affected , I have less time for the other children We never go out anymore because he is so susceptible to getting sick because of his low blood count" (AM:R33).

Mothers who had other children reported that siblings needed to learn to take care of themselves. Family activities such as going out to restaurants or shopping were suspended. Interestingly these mothers reported few problems with sibling rivalry. This may be explained by the fact that the siblings were in several cases much older than the sick child so they were not jealous of the affected child and a sense of loyalty to family members still permeates the families (Anderson, 1992). Families with younger siblings also reported no sibling rivalry perhaps because of their young age or they received attention either from the live in helpers or members of the extended families. Studies carried out by Martinson et al. (1982) and Martinson et al.(1993) on Chinese parents reported no incidences of sibling rivalry as siblings were asked by the parents to give in to or help look after the sick child. However, siblings in this study did not have to be coaxed to accede to the sick child:

> "The other children automatically give in to (the sick child) because they know he is not well..." (AM: R26).

This finding may be related to the older age of the siblings in the majority of the families and the open communication between the parents and their children. Another reason is that Chinese children who are older are taught and expected to care for and protect their younger siblings (Anderson, 1992). It is interesting to note that this finding is different from studies carried out in North America where sibling rivalry was a common problem faced by parents (Binger et al. 1969; Brown, 1989). Therefore, it appears that the close relationships within the Chinese family and the emphasis on Confucianism is important in preventing the establishment of rivalry between the sick child and the siblings.

The data suggests that all the mothers were aware of the need to normalise the family routine as soon as possible. They were aware that the time required to achieve this goal would depend on the child's condition. One reason may be that the mothers wanted to convey to the sick child that things were getting back to normal by trying to maintain the child's daily routine. This is illustrated by one mother commenting:

> "I would like the family schedule to return to normal as soon as possible. This will depend on his condition...." (EM:R53).

All mothers stated that the task of normalisation was easier if they adopted the approach of taking one day at a time. One mother commented:

> "It is easier to deal with the situation if I take things as they come. I can't plan too far in advance as I do not know what is going to happen...." (AM:R62).

According to these mothers this approach allowed them to function during the most stressful time. In this case, mothers were becoming aware of the issue of uncertainty associated with the illness and thought it best to take things as they came to maintain control. This approach has been deemed useful by professionals in coping with stressful situations (Koocher & O'Malley, 1987), and this finding concurs with a study by Martinson and Cohen (1988).

(III). Major Categories To Emerge From The Initial Interviews With The Fathers

Five categories were developed from the questions asked of the fathers and these were:

Initial reactions to the child's confirmed diagnosis of ALL

Disclosure of the child's diagnosis

Sources of support for the fathers

Changes in the family routine

The procedure for the child's admission

Initial Reactions To The Child's Confirmed Diagnosis Of ALL

Within the first category of describing their initial reactions when they first heard the child's confirmed diagnosis, two subcategories were identified and these were:

Suddenness of the diagnosis

Physical and psychological reactions to the diagnosis

Suddenness Of The Diagnosis

All eight fathers indicated that the diagnosis of the child's ALL was very sudden and unexpected as none of the children had shown any signs or symptoms of any serious illness prior to the diagnosis as indicated by the comment:

> "I felt that it happened quite suddenly, I did not expect it to be so serious because his health had been fairly good before" (DF:R10).

As all these fathers work full time, they might spend less time with the children thus neglecting the child's health status or they depend on their wives to look after the child. It is well established that in Chinese culture in particular, the man is expected to provide for the family and the woman's responsibility is to take care of the children (Bond, 1996).

Data suggested that the suddenness of the diagnosis affected the work schedule of all the fathers to various degrees. Fathers who owned their own businesses

rescheduled their work hours with little difficulty and the other fathers needed to reschedule and to ask for time off work. This is indicated by one father's comment:

> "With the suddenness of the event, things were delayed and I needed to make changes at work. I depend a lot on my co-workers to help out..." (AF:R28).

Physical and psychological reactions to the diagnosis

The physical reactions described as a result of their child's diagnosis include feeling tired. All fathers indicated that they were tired as a result of lack of sleep and adequate rest:

> "I was very tired because I went to the hospital right after work and stayed there till ten at night and the next morning I started work at seven in the morning...." (HF:R26).

Three fathers stated that they cried when they received the news, with one crying in front of his relatives and the other two fathers crying when they were alone because they did not want others to know. One father described his feelings thus:

> "At that moment, I could no longer suppress my feelings and started to cry in front of many relatives..." (EF:R4).

Interestingly, this finding has not been reported in previous studies. These three fathers may have had less hesitation in sharing their feelings as they were interviewed separately and felt safer to reveal their emotions. This is an unusual finding as it has been well established that Chinese men are reluctant to share their emotions in public

(Russell & Yik, 1996). These fathers might have suppressed their feelings and actually welcomed an opportunity to vent their feelings, which no one had provided them with.

When the diagnosis of cancer was confirmed, psychological reactions experienced by the fathers ranged from shock, fear and disbelief to guilt. All but one father reported that they felt guilty and among the reasons given was that they blamed themselves for not seeking medical advice earlier and not monitoring the child's food intake properly. This father stated:

> "Thinking back, we should have brought him to see the doctor to have blood drawn three weeks earlier but we delayed it..." (AF:R18).

One father stated that somehow his bad genes were responsible for the disease being passed onto the child. This father is convinced that genetics may have a role in cancer causation and believed that has something to do with the child's contracting the illness. These findings concurred with those of studies by Chen et al. (1987) and Martinson et al. (1993) conducted in Taiwan and in mainland China where subjects reported strong guilt feelings over their supposed inadequate parenting. The findings were also consistent with studies carried out on Caucasian parents as reported by Larson et al. (1994) and Peace et al.(1992) which suggest that parents from different cultural backgrounds experience similar reactions when they are presented with their child's diagnosis. These parents were trying to find a cause for their children's' illness

and were unable to accept the explanation that the etiology of childhood ALL is still virtually unknown.

Disclosure Of The Child's Diagnosis

The second category identified involved the issue of disclosure of information relating to the child's diagnosis. Three subcategories were identified in this category and these were:

Disclosure of the child's diagnosis to the child

Disclosure of the child's diagnosis to members of the immediate and extended family

Disclosure of the child's diagnosis to non family members

Disclosure Of The Child's Diagnosis To The Child

When the fathers were asked if they had difficulty telling the child about the diagnosis, most of them stated that the child was not told immediately on confirmation of the diagnosis because they needed time to accept the reality that the child had ALL. This is illustrated by one father's comment:

> "I did not tell (the child) right away because I needed time to accept the diagnosis myself..."(DF:R18).

These fathers were in shock and needed time to come to terms with reality and two fathers stated that they were hoping that the physician had somehow misdiagnosed the child. One father commented:

> "I did not believe the doctor's diagnosis at first, I was hoping that the doctors had made a mistake with the tests..." (EF:R16).

Four fathers decided not to tell the child the diagnosis because of their young age. This is illustrated by one father saying:

> "I do not think she needs to know because she is too young to understand..." (EF:R18).

Two of the remaining four fathers chose to tell the child a partial truth about the diagnosis. These children were both seven years old and the fathers thought that they were old enough to know that they were sick:

> "No, of course I did not tell him that he has the disease..... I told him that he has a condition in which his cells have to fight germs all the time and that it will take a long time to treat..." (FF:R18).

The reasons provided by the fathers in support of their decision to tell the child were that the child was older and would find out sooner or later from others. These fathers felt that their children already suspected that they were seriously ill because of the types of children admitted to the ward. The fathers of the two teenagers did not

actually tell them the diagnosis because they believed that they had already guessed the diagnosis:

> "My son knows the diagnosis. He once told his mother that if he did not make it to just look at it as if we had lost a bet on the stock market" (DF:R24).

These two fathers did not openly discuss the diagnosis with their children but stated that they would tell the children the truth about their diagnosis if they asked. A possible reason for these fathers avoiding initiating any discussion of the subject was to protect themselves as they did not know how to tell these children if they asked.

Fathers in the study who decided to tell the children their diagnosis reported experiencing little or no difficulty in disclosing the information to the children. The reasons given by these fathers included the existence of open communication among members of the family and that the relationships between the children, who were all males, and the fathers was good. Findings in this study were similar to those reported by Chen et al. (1987) and Martinson et al. (1993) where parents from both Taiwan and mainland China utilised a protective and open approach to revealing the diagnosis to the children.

Disclosure Of Child's Diagnosis To Members Of Immediate And Extended Family

All but four fathers reported that all members of the immediate and extended family were told and that they had no difficulty in sharing the diagnosis with them. Two fathers chose not to tell their mothers. Reasons given for not telling them were the poor health of two of the grandmothers and that it was considered not necessary to tell those who could not help the family. Among the four fathers, one father chose not to tell one of his brothers because he was not particularly close to him. One father decided not to tell his parents about the child's condition because he did not want them to worry and had instructed his brothers and sisters to keep it a secret as well:

> "I did not tell my parents because they are very old. They are both over seventy year of age and I do not want them to worry. I have told my brothers and sisters not to tell them either" (FF:R12).

Fathers with young children all chose to tell the partial truth about the child's condition to the child's siblings, and three fathers with children older than 10 chose to tell them the whole truth about the sick child. These fathers reported no difficulty in telling the other children about the child's condition because they wanted the siblings to understand why more time was spent with the sick child, thus eliminating any occurrence of sibling rivalry later. In addition, the fathers were hoping that the older children could help to care for the sick child if they

knew the truth. This finding was not reported in studies with Caucasian parents but was similar to a finding in the study by Martinson et al. (1993) where a daughter aged 15 was told of the brother's diagnosis of cancer so that she could help to look after the sick child. Therefore, a cultural implication here was that older siblings of Chinese children diagnosed with cancer are expected to accept social obligations while a relative lack of emphasis is given to independence and assertiveness (Wu, 1996).

Disclosure Of The Child's Diagnosis To Non Family Members

All the fathers were in full time employment when the child's disease was diagnosed. It was necessary to tell their supervisors of the child's diagnosis in order to get time off work. None of the fathers reported difficulty in informing people at work of the truth, and stated that people were understanding and supportive as illustrated by one father saying:

> "My partner at work is very understanding and I had no problem telling him as we have known each other for a long time" (EF:R16).

Only one father stated that he did not tell his friends because he did not want them to worry. Another father reported no difficulty in disclosing the diagnosis to others and reported receiving information and advice about the disease from his friends. The difference between these two fathers might be explained by their use of different support systems, with the former relying heavily on members of the

nuclear family and the latter father utilising other friends. It is interesting to note that the father who used his friends for support had his own business and belonged to a higher income group. The other father was a truck driver belonging to a lower income group. In addition, fathers who owned their business might also have better interpersonal and social skills than those fathers who work for others. Again this finding was supported by the study by Morrow et al. (1984) where parents from higher income groups utilised friends as support.

Sources Of Support For The Fathers

The third major category identified from the data was that of support. Three subcategories were identified within this category and these were:

Support from immediate and extended families

Support from health professionals

Support from friends

Support From Immediate And Extended Families

The fathers identified several sources of support among members of the immediate and extended family. All fathers reported that they had supported their

spouse and felt that it was their duty to provide such support. It is interesting to note that none felt they had received support from their wives. One father said:

> "I had to suppress my own feelings, my wife was on the verge of a breakdown and I had to support her. I had to be strong for her" (EF:R4).

This finding concurred with studies by Chen et al.(1987) and Martinson et al. (1993) in which the spouse was considered to be the main source of support among parents. It is not clear from the above studies whether both parents received the same amount of support from each other. In this study, all fathers stated they provided more support to their wives because they felt that they had a duty to comfort and protect their wives. Another reason might be that the wives exhibited their emotions more openly when they heard of the child's diagnosis and the husbands were obligated to provide them with support. Chinese men are often required to be strong and stoic for their wives as they are considered the head of the family (Wu, 1996).

Two fathers stated that members of their extended families provided them with support. One cited his sister as his only source of support from the extended family and one father stated his father and brothers were his main source of support. This father said:

> "My father and my brothers comforted me a lot. They provided me with a lot of support" (HF:R28).

This finding was not reported in other studies. It is the author's view that since this father lived with his father and the two brothers, he was very close to them. Other possible reasons for this might be that members of the extended family are often called and relied upon to provide support in times of need by Hong Kong Chinese parents (Hwang, 1988).

Support From Medical Professionals

Three fathers reported that they received support from the child's private paediatrician. One father stated that the paediatrician phoned and offered his support. This paediatrician was also a family friend and thus wanted to do more for the family. The other father stated that he had a friend who was a physician who worked at the same hospital where his child was hospitalised, and this physician came and visited the child at the hospital. Both of these fathers stated that support from the physicians was received in the form of information and knowledge about the disease. One father commented:

> "Friends from the medical field and (the child's) private paediatrician all gave us tremendous support by giving us information about the disease" (EF:R8).

This finding is supported by studies by Morrow et al. (1982 ; 1987) in which the medical professionals were cited as a source of support for the both fathers and mothers. It is interesting to note that in this study more fathers

obtained information about their child without difficulty. This might be explained by the difference in the physicians' attitude towards the fathers as all the physicians are male and therefore treat another man differently than the mothers.

Support From Friends

All but two fathers stated that they received support from their friends with whom they worked. Support came in the form of information shared about the treatment and the prognosis of the child's disease, advice for seeking alternative treatments and taking on the father's work load so that he could have more time with the child at the hospital. One father said:

> "My friends all told me that his condition is not terminal and that we could try alternative types of treatment....." (DF: R10).

In this present study most fathers who worked full time received support from their friends who also worked with them. The support provided by these friends was cited as being valuable to the fathers. Therefore, it appears that fathers who disclosed the child's diagnosis to their friends received help with practical issues such as asking for time off to visit their child and information about the disease.

Changes In The Family Routine

The fourth category to emerge from the data was that of changes in the family routine since the child's diagnosis. All the fathers agreed that the family routine and daily life had been affected following the diagnosis of ALL. Fathers who had other children all reported having less time to spend with the other children and that these siblings needed to learn to take care of themselves. One father said:

> "I had less time for the child and he needed to learn to take care of himself" (DF:R16).

The majority of the fathers in the study stated that changes in the family routine had been minimal. The other two fathers had older children and they stated that the other children had learned to be more independent and help out with the housework and look after each other out of necessity. Although the expectations placed on these older children whose ages ranged from 11 to 17 might sound demanding to others, both fathers agreed that the youngest child's illness had somehow encouraged the older siblings to take on more responsibility. Thus, there seems to be an expectation that older children help in the household because of the influence of Confucianism. Perhaps these fathers felt guilty because of the decreased time spent with the older children and wanted to believe that the experience of having a sibling with cancer provided the siblings with a chance to grow and to be independent.

Coping Strategies Utilised By The Fathers

The last category identified concerned the coping strategies utilised by the fathers to deal with the diagnosis of ALL in their children. Within this major category two subcategories were identified and these were:

Open communication

Use of religious beliefs and rituals

Open Communication

All fathers in the study reported that they appreciated the physicians' efforts to provide information about their child's condition. Information booklets on ALL were given to most of the parents at the first meeting with the physicians, when the diagnosis was confirmed. The treatment protocol was also discussed at this time.

> "Dr. L was very open and told us about the disease and its treatment. He was very honest and answered all the questions" (AF:R22).

This finding was supported by studies done by Lascari & Stehbens (1973) and Koocher & O'Malley (1986) in which the importance of good and honest communication between medical staff and parents was shown to be essential for parental adjustment.

Fathers who received the booklets on ALL and the treatment protocol and schedule stated that they did not have the time to read the booklets immediately after the confirmation of the child's diagnosis, but that they were useful reference material. One father commented:

> "The booklets and the treatment schedule were helpful. I do not have to guess when we need to bring him back for treatment because it is all written down" (EF:R28).

It was found in this study that the information booklets on ALL and its treatment schedule provided at the beginning of the treatment were helpful to the fathers, and four fathers stated that they were able to cope better because information was provided to them at other times during the child's treatment. One father commented on the timing of the distribution of the information booklets, and felt that it might have been better if they had been given to him later as he was too distraught to read any of the booklets at the time. Findings such as this further highlight the difficulty of deciding the best time to give information regarding the child's disease and treatment regime to the parents.

Use Of Religious Beliefs And Rituals

Four fathers stated that they had practiced a daily ritual of incense burning and the offering of simple gifts of food and drink to the deities occasionally before the child's diagnosis, but that the frequency of such practices had increased after the

confirmation of the child's condition. These fathers found the ritual of incense burning provided them with a sense of hope as illustrated by one father who said:

> "I burnt incense in the morning occasionally before she was sick but now I am doing it daily in the hope that she will recover" (EF:R44)

This finding was consistent with the studies undertaken by Martinson & Martinson (1988) and Martinson et al. (1993) on Chinese parents in which parents increased their previous frequency of worship following the diagnosis of the child's illness. In the author's opinion the use of religious rituals, in this case incense burning by fathers to bring luck to the families might be explained by the convenience of practice, as fathers who use this form of worship all stated that an altar had been set up in the home for this purpose. There were limited visits to the temples as this would take up too much of the fathers' time which could be spent with the sick child.

In addition to the burning of incense, one father reported consulting with a fortune teller, using the eight characters which represent the child's hour, day, month and year of birth. This consultation was done over the phone as the fortune teller lived in mainland China. The information gained in this way provided this father with hope and support.

> "I phoned a fortune teller in the mainland and told him my son's time and year of birth and nothing else. He told me that he was destined to have such an illness because he had angered some gods but that he would survive the ordeal.... This gave me a sense of hope..." (DF:R30).

The religious activities demonstrated by these fathers represent an effort by them to assert some kind of control over their own destiny at a time when they stated they felt virtually helpless. These fathers also felt that they were doing something active to help their child and to regain some control over the situation.

(IV) Comparison Of Categories Found Between The Mothers And The Fathers

Four categories were identified in both the fathers and the mothers' transcripts and these were.:

Initial reactions to the child's confirmed diagnosis of ALL

Disclosure of the child's diagnosis

Sources of support for the parents

Changes in the family routine

Within the same categories identified by both mothers and fathers, there are many similarities but there are also important differences. Each of these categories will be discussed in the following section:

Initial Reactions To The Child's Confirmed Diagnosis Of ALL

The mothers reported experiencing a wider range of psychological reactions than the fathers. All the mothers stated that they were unprepared to accept the diagnosis of ALL initially, but this unprepardeness was not universally found in the fathers. Perhaps the mothers in this study were more optimistic than their spouses, as their unprepardness to accept the child's diagnosis prompted them to seek alternative explanations for the child's symptoms. Other possible reasons for this difference is that the mothers might have used denial as a coping mechanism more effectively than the fathers and the fathers in this study have been more willing to accept the physician's diagnosis than the mothers. As one father said:

> "I was sure my child had cancer or something serious because I was sure that the doctors would not have admitted him if there was no need..." (DF:R63).

In the author's view, the fathers in this study did not use denial as an active method of coping or they explained their child's illness as "fate". Fatalism is known to be used as an effective coping strategy in the Chinese culture (Crittenden, 1996). As illustrated by one father:

> "I believe that everyone has to undergo certain hardships and it is fate that my boy has to have his hardship so young...." (EF:R30).

Other researchers might question whether the fathers in this study were sharing their true experiences with the researcher as it is known that Chinese people have

reservations about sharing their feelings with strangers (Phillips & Pearson, 1996). However, the author felt that the fathers all seemed to be willing to share their feelings, with a few admitting that they actually cried when they learned of their child's diagnosis. Perhaps the author gave these fathers a chance to vent their feelings.

The fathers' physical reactions to their child's diagnosis appeared more severe than their wives'. This can be explained as all except one of the fathers worked full time and continued their work after the child was diagnosed, whereas the majority of the mothers stayed at home with the child. Some mothers were able to obtain help from members of their extended family and their live in help. None of the fathers stayed overnight with their child in the hospital but all would visit after work despite the time. This is illustrated by one father saying:

> "I always go to the hospital to see her after work, even when I return from my overseas trips, sometimes at two in the morning. I need to see her before I go home, I just want to see that she is all right.." (EF:R28).

Although none of the fathers stayed overnight with the child, some stated that they were more involved in looking after the sick child and their other children in addition to their job. Thus, the demands of work and the extra responsibilities of taking care of the children created more physical stress and conflict for these fathers. This stress was more severe for one father, who described having to increase his hours of work in order to bring in more income:

> " I had to increase my working hours, so I could afford to buy good quality food for my son..." (DF:R36).

Disclosure Of The Child's Diagnosis

In this category there are more similarities than differences when comparing the responses given by both parents. Both the mothers and fathers in this study described the need for members of the immediate and extended family to be informed of the child's diagnosis and stated that they had little or no difficulty in doing so. Both fathers and mothers who worked full time reported no difficulty in telling their supervisors and their co-workers about the child's diagnosis. Mothers were more worried that other children may disclose the diagnosis to their friends at school or to the neighbours, whereas the fathers did not seem to worry. This might be explained by the mothers' desire to protect the children and the siblings from being ostracized by their friends at school. One mother stated:

> "I went to see the social worker at the social welfare department and she asked me the diagnosis of my child. When I told her, she immediately asked me if it was contagious...." (IM:R73).

This further illustrated the fear of some mothers in this study of letting others know of their child's diagnosis because of the stigma attached to the disease (Walsh-Burke, 1992).

Both fathers and mothers in this study stated that they decided to either withhold or disclose the truth about their child's illness depending on the age of the child. The older children were often told of their diagnosis whereas children under the age of three were not informed of their diagnosis. This applied to the other siblings as well. Therefore, both parents agreed in principle to tell their children the truth if they were older. However, one of the mothers was more upset than her spouse that the teenage child found out the diagnosis by overhearing some medical students discussing his case during ward rounds. It is interesting to note that this child's father and mother experience different levels of distress upon finding out how their child discovered his diagnosis. The parents of the other teenager also reacted differently when their son told them that he knew that he had ALL after watching a programme on television. The father in this case was more upset than the mother as illustrated by the father saying:

> "He (the child) told me that if he died, we could just forget him and treat it as if we had lost a gamble on the stock market. I was very upset..." (DF:R36).

One possible reason for the difference between the mother and the father's reaction in this case was that the mother was trying to comfort the child and therefore needed to suppress her feelings at the time. Therefore, mothers and fathers of these two teenagers reacted differently when their children revealed to them that they were aware of their diagnosis.

Sources Of Support For The Parents

Seven of the mothers in this study agreed that their spouse had provided them with a great deal of support and cited them as their main source of support. However, the fathers did not feel that their wives had provided them with enough support. The reason given by all the fathers was that it is the husband's duty to be strong for his wife. This illustrates the role expectations of men and women relating to the provision of support in the Chinese culture in times of need. Both parents stated that the spouse was their main source of comfort and support. However, all the mothers disclosed that they received more support from their spouse than the fathers who did not feel that they received equivalent support from their wives. All but one mother cited members of the extended family and in particular their mothers, as major sources of practical support. However, only two fathers stated that their fathers gave them support, and in these cases , these fathers live with the families.

A major difference within this category is that the fathers in this study tended to use religious rituals as a major source of support whereas this was only cursorily mentioned by the mothers. Possible reasons for this might be that the mothers were less religious than the fathers, as one mother said:

> "I am a Catholic but I have not practiced for a long time, even since (the child's) diagnosis..." (DM:R68).

Also, several mothers depended on their own mothers to perform religious rituals such as going to different temples, and asking for a cure for their child so as to allow them

to have more time with the sick child. These findings are similar to the results of a study undertaken by Chen et al (1987) with Taiwanese parents, in which the grandmothers went to the temples to pray for the recovery of the child. However, in this study grandmothers went to the temples without being asked by the mothers to seek help from religious deities.

Changes In The Family Routine

The data obtained from both the fathers and mothers demonstrated that the family's routine had been affected since the child's diagnosis. More mothers than fathers stated that the family schedule had been affected. The mothers who stayed home were more likely to have had their whole schedule affected because they were at the hospital with the child all the time and the sick child became the center of their attention. In the second interview all the mothers revealed that they spent the majority of their time in the kitchen as the families rarely ate out, and that they believed that it was better for the child to have nutritious home made soups. This finding concurred with the study by Chen et al. (1987). However, the data from both parents showed that these changes were perceived as minor and did not seem to create many problems. In the second interview both sets of data showed the family routine getting back to normal slowly as the children no longer required hospitalization. This was a great help to the parents who lived far away from the hospital, saving the family time and money and allowing more time to be spent with the other children.

The increased time spent with the sick child reported by all the fathers resulted in the development of a closer relationship between the fathers and their children. However, this was not reported by the mothers. For the mothers who were full time homemakers, their time spent with their children was minimally affected after the children became sick since they had always taken the major responsibility for caring for the children, and their relationships with the affected children had always been close.

The fathers and mothers reported utilising different coping strategies to deal with their child's diagnosis. Fathers tended to use more active methods for coping such as information seeking and the use of religious ritual whereas mothers coped by using more passive means such as taking life one day at a time and channeling all their energy into the sick child. These differences may be explained by the difference in personality between the mothers and fathers in this study and the fact that Chinese men are traditionally more aggressive in seeking a solution to a problem (Bond, 1966). Therefore, Chinese men are more inclined to use problem focused coping whereas Chinese women tend to use emotion focused coping (Phillips & Pearson, 1996).

Summary

The experiences of a small sample of Hong Kong Chinese parents of a child diagnosed with ALL were explored in this study. Certain factors such as the length of time required to confirm the child's diagnosis, the availability of support to the parents and the individual personality of the parents all influenced the parents' experiences. Their coping methods were also identified.

The parents' initial reactions of fear, anger and disbelief when the child's diagnosis was confirmed were found to be generally similar to those of their counterparts living in mainland China, Taiwan and North America. Although the cultural context is different for all these countries, there are certain common factors which were experienced by all the parents. This further reinforced the belief that because cancer is a life-threatening illness, parents are put in a state of anticipatory grief fearing the potential loss of their child even with the improved treatment modalities. Both the fathers and mothers in this study reported using different coping mechanisms after the confirmation of the child's diagnosis. The majority of the fathers appeared to use problem focused coping strategies by actively seeking information from the physicians about the children's prognosis and one father consulted a fortune teller to learn the fate of the child. The use of religion was reported by the majority of the fathers to be an effective means of coping. Mothers however, found emotion focused coping strategies to be effective. They believed in taking one day at a time and focussed entirely on the needs of the sick

child. All mothers stayed with their child at the hospital initially and all fathers came to visit the child after work.

The main support for the majority of the mothers came from their spouse and they reported that they were satisfied with the amount of support they received from their husbands. The fathers on the other hand stated that they would like to receive more support from their wives. For two fathers the main support came from members of the extended family. Extended families, friends and medical professionals were also sources of support to the parents in this study. Most of the parents received assistance and support from members of the extended families, and parents who work full time stated that they received help from their co-workers in the form of taking on their share of the work load. All mothers stated that the consultant and medical professionals were supportive, especially when the child was first diagnosed but only two mothers commented on the support they received from the nurses. All the fathers on the other hand stated that the physicians were helpful in providing information, but no comment was made about the nursing staff. The availability of live in help was beneficial to some families in which the helper relieved the mothers of household tasks.

Some of the fathers exhibited more guilt than their wives in this study. Perhaps these fathers felt that they had not been spending enough time with the child. Therefore, when the child was diagnosed with cancer they felt that they

were to blame and experienced more guilt than their wives. This feeling persisted even though they were reassured by the physicians that the cause for ALL is still unknown.

In summary, the experiences of Chinese parents of children with ALL is similar to those of parents in other countries. The difference in the use of coping mechanisms is related to cultural differences such as the use of different religion and folk beliefs. These parents' experiences had more similar similarities than differences with parents from other countries.

(V). Differences between the initial and second interviews

A few differences were noted between the initial and the second interviews. The second interviews were much shorter than the initial interviews, the average time for he second interview was 30 minutes. All the parents except one mother appeared more relaxed at the second interview, and stated that they felt less anxious because the children were responding well and were experiencing minimal side effects from the treatment. The children's improved physical condition had a positive effect on the parents' experiences, as the hope of curing the child's disease was boosted. The one mother who responded differently had had her child admitted to the intensive care unit because of an infected central line. She stated that her experience had deteriorated. This mother did not work and had been

relatively isolated since the diagnosis of the child's condition as her family did not reside in Hong Kong. In addition, this mother felt that her need for information was never met by nursing staff in the intensive care or the oncological unit. Therefore, parental experiences in the second interview were influenced to a large extent by the physical conditions of the child and the availability of support. All the mothers who had worked full time had returned to work by the time of the second interview and the family routines were slowly getting back to normal. Mothers who were full time homemakers reported that they were busier now that their children were at home as they spent more time making nutritious soups and making sure that the child was getting adequate rest. None of these mothers complained about the extra work and felt good that they could contribute to the recovery of the children.

In the second interview, two sets of parents stated that they were experiencing financial difficulty and were applying for financial assistance from the Government. It is of interest to note that in both cases, the mothers revealed such a difficulty to the researcher. The reluctance of the fathers to admit to having financial problems is due to the fact that traditionally they are the breadwinners of the families. By admitting having financial difficulties, their ego would suffer and they would be afraid of what other people might think of them. The financial difficulty arose from the extra expenses incurred because of the children's illness and they were entirely non-medical in nature. Expenses included taking taxis to

and from the hospital with the sick child and buying expensive foods to build up the child's immunity.

Fathers who had reported using religious rituals as a main source of support in the first interview were continuing their ritual of incense burning. The father who had consulted a fortune teller from the mainland of China was less inclined to consult other fortune tellers to seek reasons for his child's illness. This is probably related to the continuous improvement of this child's condition and the fact that he appeared to be responding well to the treatment with minimal side effects.

In conclusion, during the second interview the majority of the parents stated that they felt better because their child seemed to be responding well to treatment. The parents were all more optimistic when their children were doing well and stated that they believed the chance of curing the disease was high. None of the parents minded the frequent trips to the hospital because the treatment was relatively mild in comparison to the initial treatment phase. Mothers who were concerned with the uncertainty of the child's future all stated that they were more optimistic because of the child's improved condition. Therefore, on a whole the parents were more positive and their families were generally returning to normal.

Chapter 5

Conclusion: Limitations Of The Study And Recommendations For Practice

Limitations Of The Study

This study utilised a qualitative approach to the research design to elicit an understanding of Hong Kong Chinese parents of children with ALL through the use of semi-structured interviews. The author recognises that the use of such an approach does not allow the findings to be applied to other samples of Hong Kong parents with a child diagnosed with ALL. In addition, because interviewing was chosen as the main method of collecting data for this study, the researcher needed to familiarise herself with interview techniques. Therefore, interviews that were carried out at a later date benefited from the continuing learning process which may have enriched the depth of the data.

Several precautions need to be observed in interpreting the results. First, the data was generated by interviews with parents whose children were admitted and treated at a single large teaching institution. The results might be different in hospitals with different facilities, which may affect parents' reactions. Due to the scheduling of the initial interview, the accuracy of the data depends on the parents' memory, because they were interviewed at least one month after the confirmation of the child's

diagnosis. The researcher also had to be aware of becoming too involved during interaction with the parents because this would affect the interpretation of the data. Therefore, the researcher needed to consciously remind herself of her role in the study and to avoid selectively attending and responding to certain information.

Another limitation of the study was related to the interview schedule being too structured. This might negatively impact on the data obtained as parents were not given the opportunity to express their views freely because of the types of questions being asked. Thus, the design of the interview schedule might have affected the depth of the data collected from the parents and inexperience conducting the interviews prevented the researcher from picking up cues from the parents.

The lack of an appropriate venue at the hospital to interview the parents created yet another limitation for this study. Although the parents were allowed to choose the venue for the interview, the majority of them chose the hospital for both the initial and second interviews which were scheduled when the children were back at the hospital for follow up in the outpatient department. Parents were interviewed either in the ward's hallway or in the waiting area of the outpatient department. Neither of these two venues were ideal as there were a lot of distractions, all of which were beyond the control of the researcher. Therefore, the researcher had to keep in mind that the presence of such distractions might affect the quality of the data collected and every

effort was made to interview the parents in the evening when the amount of noise was less and the child was settled for the night.

Every effort was made by the researcher to interview the parents separately and the reason for this arrangement was given to the parents at the first meeting. However, one set of parents who chose to be interviewed at their apartment chose to remain together for part of the interview. Thus, the presence of one spouse might have had an effect on the responses given by the other spouse. The researcher took special care when interviewing this couple and transcribing their recorded interviews. In this case the use of field notes is of particular importance in aiding the interpretation of data. It was however extremely important to respect the wish of this couple and to not pressure them into acceding to the researcher's advice. However the author acknowledges that the situation may have influenced the categories emerging from this set of data.

Another limitation of the study related to the lack of data received from the second interview with these parents, as one of the objectives of the study was to compare parental experiences at two different points in the child's treatment regime to see if the parents required different nursing interventions at these times. Few comparisons can be made due to a lack of information received from the parents. One possible reason for this may include the timing of the second interview, in that the children were doing well and were in remission at that time, and the parents no longer reported having

feelings of anxiety and stated that everything was getting "back to normal". In the second interview, the mothers spent the majority of the interview time stating that they were feeling better now that their children did not require prolonged hospitalization. Therefore, the data obtained from the second interview was not as rich in detail as the data from the first interview. Also, due to the depth of the data obtained from the first interview, the researcher placed extra emphasis on reporting the findings obtained from those interviews. The researcher acknowledges that this lack of information demonstrates the problems of the interview schedule and that a different interview schedule would perhaps be more appropriate for the second interview.

A final limitation rests with the issue of translation. The parents were all interviewed in Cantonese and some terms used by the parents were difficult to translate into English because of the differences in the cultural and linguistic context. When religious beliefs were discussed, the researcher attempted to overcome the translation problem by consulting literature on the topic and discussing with colleagues who were familiar with the topic. The author is aware that this may pose a threat to both the reliability and validity of the study. Despite these limitations noted in the study, some important and valuable implications for nursing practice and further research have been identified and these will be discussed in the following sections.

Implications for Nursing Practice

The results of the study are significant in informing nursing practice and the following points provide some suggestions as to how the results might be utilised to make an impact on the provision of nursing care to these children and their parents.

The analysis of the data indicated that a thorough assessment of family factors, including coping resources and responses, past history and concurrent stresses was essential to gaining an understanding of parents whose children had been admitted with a life-threatening disease. This assessment is of prime importance in planning nursing interventions and providing adequate support to the families. However, it is important that health care professionals do not interview the parents too many times as noted by some fathers in the study. The effects of repeated interviews and fatigue can cause the parents undue anxiety at a time when they want to be with their children. The designation of a primary nurse and physician to the child would help in this area, as those designated could decide the most appropriate times to interview the parents most effectively.

The unwillingness of some nurses to teach the parents and to share information about the status of their child's condition was generally attributed to the demands made on nurses due to excessive numbers of clients. One possible reason for nurses in Hong Kong to be reluctant to disclose information is that they believe that this is the

physician's responsibility and are afraid to intrude on the physician's territory. Therefore, it would be helpful if the consultant and the nurse in charge of the unit could develop special guidelines defining the nurses' role relating to education of and information disclosure to the parents and the children. Nurses working in the unit should offer their expertise and intuition and contribute to developing such guidelines. This recommendation demonstrates the need for greater autonomy for nurses and to establish interprofessional collaboration between medical and nursing staff. However, support from peers and nursing administration staff is essential.

All parents stated that the initial conference with the physicians was helpful to their understanding of their child's disease. The unit has adopted a multidisciplinary approach to caring for the children, and it would be beneficial if a nurse were to participate in this initial meeting between the parents and the physicians. Findings from previous studies demonstrate the significance of the use of regular meetings between parents, children (of appropriate age) and medical and nursing professionals as a means of informing parents of their childrens' progress (Binger et al. 1969; Martinson et al. 1993).

Recommendations For Future Research

No previous studies were identified locally or in other countries which explored the experiences of Hong Kong Chinese parents of children with ALL. This study provides a starting point to explore this area but further investigation of parents' experiences of having a child with ALL or other cancer and in other hospitals is recommended. This is in order to gather more diverse viewpoints from parents of children of different types of cancer as the treatment modalities are different and this might have an effect on the parents' experiences

Quantitative studies may be used to test theory relating to the experiences of parents of children with ALL based on the similarities and differences between studies from different cultures. Thus, the use of different research designs can further the understanding of parents' experience of having a child diagnosed with cancer. The number of parents included in future studies should be increased and single parents should also be recruited into the studies so that both single mothers' and fathers' experiences may be compared with those of other parents. Such studies of single Chinese parents are warranted as the number of couples getting divorced has increased from 4,086 in 1984 to 7,735 in 1994 (Wu, 1995). With Hong Kong being a part of mainland China after June,1997, it would be valuable to conduct comprehensive studies on Chinese parents in mainland China and those in Hong Kong to see if living

environment and cultural factors would have an effect on the experiences of these parents.

Future studies should include the experiences of other members of the immediate and extended families, such as the affected child, siblings, grandparents and health care professionals in order to obtain a more comprehensive view of the impact of cancer on the family. Indeed data from this study indicates that the experiences of members of the nuclear and extended families will affect the experiences of the parents. The inter-relationships between members of the immediate and extended families and health care professionals need to be further studied.

Conclusion

In conclusion, this qualitative study served the purpose of exploring the experiences of a small sample of Hong Kong Chinese parents of children diagnosed with ALL. It identified certain factors that influenced their experiences and the ways in which they coped with the diagnosis. The experiences of these Chinese parents were found to be generally similar to those of their counterparts living in mainland China, Taiwan and North America. Although the cultural context is different for all these countries, there are certain common factors that are experienced by all the parents. These include the initial response to the child's diagnosis, the different

coping strategies used by the parents and the use of people outside the nuclear family for help and support.

The findings of this study also demonstrate that the experiences of most of these parents were not entirely negative. The parents discovered that they could cope with the situation utilizing a variety of support systems available to them. The literature has shown that nurses may be one of the sources of support for these parents, although only two mothers in this study identified nurses as a source of support. The findings of this study demonstrate that where nurses provide support this tends to focus on the mothers and not the fathers. The needs of the fathers must be acknowledged and assessed in order that comprehensive care can be provided to the entire family. The results of this study will contribute to future research in the area of paediatric oncology in Hong Kong.

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APPENDIX I

PERSONAL DATA FORM

Name: Code:

Age:

Marital Status: Single

Married

Divorced

Widowed

Educational Level: Completion of Primary school

Completion of Secondary school

Completion of Matriculation

Completion of Tertiary or above

Employment Status: Employed Self-employed

Unemployed

Retired

Occupation:

Monthly income:

Religion:

APPENDIX II

Semi-Structured Interview Guide for Parents of Children with Acute Lymphocytic Leukaemia

Informant:

Interviewer:

Date:

Time:

Venue:

Type of interview: (1 st. or 2 nd.)

1. How many children do you have, and how old are they?

Genogram:

2. Can you tell me what happened when_____ was diagnosed?

   When was that?
   Symptoms?
   Any other unusual occurrences?
   Prognosis given at the time and by whom?

3. What were your reactions and how did you feel at the time?

4. How did you deal with your feelings?

5. Did you receive any support at that time?
   5a. Is there anything that might have made this period a little less stressful for you?

6. Did you tell your child about his/her condition?
   6a. Was there anything you did not tell the child and why not?
   6b. What was the child's reaction when you told him/her the diagnosis?

7. Did you tell the rest of the family about the child's condition and did you encounter any problem?
   7a. Spouse (or the other parent if separated)
   7b. Other children
   7c. Members of extended family

8. Did you tell your relatives and friends about the child's diagnosis?
   8a. Was it difficult?
   8b. How did they react?
   8c. Were they helpful? How?
   8d. What was most helpful? Give an example if possible.

9. Could you remember anything else that happened at the time of the diagnosis?

10. What have been the toughest times or problems during the child's illness?

11. Are there any positive or negative things that have come out of this experience, for yourself and your family?
   11a. Did you discover any strengths?
   11b. Did you develop any new support ties and system?

12. In general, how do you feel you're handling the situation?

13. How long has the child been in hospital?
   13a. What were the types of treatments?
   13b. Did you stay with the child in the hospital?
   If yes, who took care of the family?

14. Did you have any problems with the medical or nursing staff in the hospital?
   14a. Emergency room?

15. Did you ever think of preventing certain procedures from being done to the child? If yes, what happened?

16. I know it is difficult to think about the future, but when you think of your child's future, what sort of things come to mind?

17. When you wonder if your child will survive, are there things that help you feel better, or more optimistic?
    17a. Is there anyone that can help you at this time?

18. Do you have any religious beliefs? If yes, have they changed since the onset of the child's illness? Have they helped you through the difficult times?

19. Do you ever wonder why this has happened to your child?

20. Has your child's illness affected the family's routine and how?

21. Has the illness affected your job and who is responsible for _____'s medical care?

22. Has the illness affected the quantity and quality of time you spend with the other children?

23. Has your family changed in any ways since the onset of _____'s illness?
    22a. Has the family grown closer or has it grown apart?

24. How do the other children feel about _____'s condition?
    24a. How do they feel about_____?
    24b. Do they understand the seriousness of the illness?
    24c. Do they show any reaction when_____gets special treatment or attention from you?
    24d. Do you think they learn anything from the situation?

25. Has the illness affected your daily routine?

26. Have you had to change your goal as a result of _____'s illness?

27. Do you have to cut back on your working hours and do you have the support and understanding from your co-workers and supervisors?

28. After the diagnosis, did you inform the school? If yes, who did you talk to?
    28a. Were the classmates told?

29. How is _____'s classwork now? Are there any differences in the child's work and what do you think contribute to the differences?

30. Has _____experienced any special problem at school since the diagnosis?
    30a. If yes, give some examples.
    30b. Has _____ missed much school?
    Illness?
    Low blood count?
    Treatment related side effects?

31. If there was available access to a social worker, nurse or a psychologist, would you have wanted to talk to them and which would be your preference?

I understand that some parents and patients get to know each other pretty well and that they help each other through difficult times.

32. Suppose you were asked for advice, what would you say to parents whose child has just been diagnosed with the same disease as your child?

33. Is there anything you want to add before we end this meeting which could to help me understand your experience a bit better?

THANK YOU VERY MUCH FOR YOUR TIME

APPENDIX III

CONSENT FORM

for the study of
The Experiences of Chinese Parents of Children with Acute Lymphocytic Leukaemia (ALL)

This study is designed to provide some insight into the experiences of Chinese parents of children diagnosed with Acute Lymphocytic leukaemia. It is hoped that this study will assist medical professionals in planning appropriate care to meet the needs of these children and their parents.

If you agree to participate in this study, you will be interviewed twice within a period of four months. Interviews will be audio-taped and all information will be kept confidential. Participation is on a voluntary basis and you can withdraw from the study at any time. Your decision to not participate in the study will not affect your child's treatment. If you have any questions, you can contact the researcher Betty Wills (Tel: 26096229)

I,_____, have read and understood the contents of the consent form, and have had the opportunity to ask questions. I know participation is voluntary and that I can withdraw from the study at any time. I understand refusal to participate will not affect my child's treatment.

Date : _____

Parent's
Signature :_____

Researcher's
Signature :_____

同意書

了解患有白血病的中國兒童的父母的經驗之研究

為了盡力協助患有白血病的兒童及其父母應付疾病和回復正常的生活，醫生、護士及其他醫護專業人員必須了解白血病兒童的父母的經驗。這項研究的目的是透過訪問，以明白你的感受。希望醫護人員可以掌握這些資料，從而作出適當的計劃，以幫助你的子女。

這項研究所得的資料，將會絕對保密。一切資料只會用作研究用途，並不會對你的子女所接受的治療有任何影響。此外，你可以隨時退出這項研究，如對研究有任何疑問，可與本人韋陳淑嫻(電話7666422)聯絡。

本人，_____，已參閱及明白同意書的內容，並擁有發問之機會。本人知道參與研究是出於自願，並且可以隨時退出這項研究。本人明白參這項研究，絕不會對本人的子女所接受的治療有任何影響。

日期：_____　　病人簽署：_____

研究員　：_____

APPENDIX IV

SAMPLE TRANSCRIPT

Informant: AM (mother - family A)

Interviewer: BW

Date: 1.2.94.

Time: 15:00

Venue: AM's residence

Type of interview: First

*Key: Interviewer: INT.
Informant : CLI.

INT. 1 How many children do you have, and how old are they?
CLI. 2 I have four children, three girls and a boy. The oldest girl is 20, the next girl is 17, the youngest girl is 12 and the youngest child is three.

Genogram:

INT. 3 Can you tell me what happened when M.T. was initially diagnosed?
CLI. 4 He was diagnosed with ALL in December by the paediatrician. He had been followed by this doctor regularly since he was born. The last time he went to see the doctor, he had commented that his colour was not very good and ordered a blood test.

My husband took him to the doctor. When he told me later I figured it was because M.T. does not like to eat a lot of meat. I thought because of a lack of red meat intake, it was not unusual for his colour to be a bit poor.

At the time, he had a cold and I thought it was best to wait till his cold was better before we took him for the test.
After 2-3 weeks, M.T. experienced some problems with his digestive tract.

He had diarrhoea when he took milk. We brought him to see the doctor, the doctor again commented on his poor colour and told us not to wait till he got better. He wrote the order for the blood test and the report was out the next day revealing some abnormal cells.

(At this point, the client rephrased her information, stating that the reason for bringing M.T. to the doctor was for a cold.) I thought all along the poor colour was due to the poor intake of meat, he only likes to eat eggs.

I took him in on 30/12 to see the doctor because of his digestive problems. He had diarrhoea and did not seem to tolerate milk, the doctor ordered medication for his diarrhoea and we went home. After we went home, he did not want to eat and started to vomit, it was about 22:00, we took him to the hospital. They paged Dr.L (our regular paediatrician) but he had just left the hospital and was unable to see M.T. He suggested the doctor on duty should check him, this doctor stated that M.T. was suffering from a stomach ailment and prescribed some medication for him. A suppository was inserted via the rectum to stop his vomiting. He took the drugs for two days and appeared to be better. He was able to keep congee down for the next two days.

It was then time for him to go back to Dr. L. for his follow up, we told him about the stomach problem and he stated his colour was worse than before and suggested blood tests right away and that we should not wait till he was better.

As it was already 18:00, the doctor asked us to return the next day but I said we wanted to go to the hospital for the test. The doctor wrote the order and asked us to phone for the results the next day.

My husband phoned him around eleven the next morning and we were told to bring M.T. into his office and then he would be transferred to the hospital.

The doctors were off for the next two days because it was New Year, so treatment was delayed and did not start until 3/1.

The BMA was done on the third and ALL was confirmed, treatment commenced immediately. The prognosis was first hinted at Dr.L (our private paediatrician), he comforted us and told us that the prognosis for this illness in his age group is quite good.

INT. 5. What were your immediate reactions and how did you feel at that time?

CLI. 6. I was frightened, very frightened, I never dreamed that he had such a disease. Moreover, when I found out about of the disease I was very scared.
I did not understand his condition, they said that he had a disease of the blood.
I knew they meant cancer of the blood, I was scared and I did not know how the disease was treated.

There is no way around the problem, the doctors said that we should trust them and follow their advice. The doctors would decide what to do and we must follow them.
We handed over responsibility to them.

INT.7 Did you receive any support at the time, if so from whom?
CLI. 8 Just my husband, nobody knew the truth. My husband gave me a great deal of support.
My 17 year old daughter was at home at the time and she cried upon hearing the news. I did not have to tell her. The father came home after talking with Dr.L. and broke the news about the blood work to us. An admission form and the blood work results were given to us by Dr. L. and we had to get M.T. ready and off to the hospital. My heart sank and I felt really bad then.

I experienced the worst feelings that day, I was not happy on his admission day. I did not undersrtand the seriousness of his condition, I just knew that he had the disease.

I was very scared. He was crying and the unfamiliar surroundings upset him, he even refused to sit or sleep in the bed.

INT. 9 Could the nurses and doctors have done more to alleviate your concerns and help you at that time?

CLI. 10 I guess besides supporting and comforting us there was not much they could do.
We did not know anything about blood cancer. All we knew about this disease was that it was very dangerous and some forms of blood cancer are fatal. We did not know there were so many forms of blood cancer.
Perhaps, if there were more pamphlets telling us about the different types of blood cancer, this would be helpful.

INT. 11 Did you tell M.T. about his condition?

CLI. 12 No, he did not know but sometimes when I cried, he would look at me.

INT. 13 Did you tell the rest of the family about M.T's condition, if so how did you approach this task?

CLI. 14 My 17 year old daughter is aware of M.T's diagnosis, I did not hide anything from the other children. I told the children M.T's condition and they were all very upset.

All my brothers and sisters are aware of his condition, there are four of us. I am the oldest and we all live in H.K. I phoned them and let them know. They were all very scared and came to see M.T. that night in the hospital.

INT. 15 Did you share the diagnosis with relatives or friends?

CLI 16 All my husband's relatives are in Canada, all his brothers and sisters are aware of his condition except M.T's paternal grandmother.

At the time when M.T. was sick, one of my husband's brothers was visiting and there is no way we would hide the news from him.

INT.17 Did you experience any guilty feelings about M.T's condition?

CLI.18 Yes, when I was expecting him, I came down with pneumonia and I had a chest X-ray done. I think this is the reason why he has the disease. Er... I was reassured by the doctors that this is not the case but I still think because of that test he had to go through a lot of pain.

When I was pregnant with him, I was very reluctant to get the x-ray but the doctor at the time reassured me that I would be provided with a lead apron for protection and that his own wife also had a chest x-ray while she was pregnant with his daughter and that she was all right.

APPENDIX V
MATRIX ON MOTHERS (FIRST INTERVIEW)

Mother's code & working status **H- home** **W- work** **Age of mother**	**Age & gender of child** **M-male** **F- female**	**No. of siblings**	**Reactions to child's diagnosis**	**Signs & symptoms**	**Who informed of Diagnosis initially and term used by doctor**	**Disclosure of child's diagnosis to family**	**Disclosure of diagnosis to child**	**Who give you the most support**	**Changes in the family routine**
AM (H) - 45	3 M	3 - all older - 21,17 & 12	Frightened, very frightened ,cry, so sudden	Diarrohea, stomach flu - vomiting. Colour poor - "white"	Doctor L (child's own paediatrician) -suspect ALL, confirmed by specialist in PWH - Disease of WBC	Yes - except paternal grandma (overseas and not well)	No - too young	Husband then own mother - help with household task	Yes, unable to go out on weekend with family can't take care of younger child
BM (W) - 28 Work in Japanese bank - senior clerk - 8 years	2 F	0	Cried a bit, scared but relieve, calm	Pain in abdomen	Doctor at KWH, confirmed by specialist at PWH Disease of WBC	Yes	No - too young	Husband and then friends at work	Yes, did not go to work
CM (W) - 48 Work as kitchen helper at HKUST	14 M	3 - older - 19,17 & 15	Frightened, did not know what to do, too sudden	Flu like symptoms	Doctor at UCH, confirmed by specialist at PWH Disease of WBC	Yes - except paternal grandma (Alzheimer's disease)	No - child know from watching TV	Husband	Quit job - stay with the child
DM (H) - 43	6 F	1 - older - 8	Scared, cry, nervous sudden , did not know what to do - (Thyroid condition)	High fever, sore throat	Paediatrician at UCH and confirmed by specialist at PWH - Disease of WBC	Yes - except paternal grandparents - too old	Partial truth - ill and needed treatment	Husband then own mother - help with other child	Unable to care for other child
EM (W) - 38	13 M	1 - younger - 11	Calm, not too upset did not know seriousness. Happen too suddenly	Bone pain, colour poor, tired	Specialist at PWH - Disease of WBC	Yes	No - find out from medical students	Husband	Quit job - spend all the time at the hospital
FM (W) - 28 Hairdresser	2 F	1 -older - 4	Scared, cry, denial, helpless and hopeless	Fever, poor colour	Doctor at BH, specialist at PWH Disease of WBC	Yes	No	Husband	

GM (W) -28 Insurance broker	5 M	1 - younger -2	Scared, cry, denial wanted second opinion	Fever on and off for 1 week, colour pale and skinny	Specialist at PWH- Disease of WBC	Yes	Partial truth - worms in abdomen	Husband	Take time from work - unable to care for other child
HM (H) - 27	11 month F	0	Scared, cry, denial cannot believe what was being told	Fever, rash on face	Specialist at PWH - Disease of WBC	Yes	No - too young	Aunt - in H.K.	Spend all time at the hospital
IM (H) - 36	9 month M	3 - older -9,7 & 5	Scared, denial	Cough, cold	Doctor at PWH - Disease of WBC	Yes	No - too young	Maternal grandma- in mainland China	Spend time at the hospital and unable to care for the other children

MATRIX ON FATHERS (FIRST INTERVIEW)

Father's code Age Occupation	**Age & gender of child**	**Reactions to child's diagnosis**	**Signs & symptoms**	**Who informed Diagnosis initially ?**	**Disclosure of child's diagnosis to family?**	**Disclosure of diagnosis to child ?**	**Who give the most support ?**	**Changes in the family routine**	**Rel'ship with staff**
AF - 48 Pharmacist owns business	3 M	Shock, disbelief	Diarrhoea, fever, stomach flu	Paediatrician on the phone, confirmed at the treating hospital	Yes - except own mother (not well and not in H.K.)	No - too young	Wife, mother-in-law, friends in the medical field	Do not eat out, busy -in after work - tired	Doctors are helpful- inform
BF - 30 Stock market broker	2 F	Shock, too sudden, can't believe is happening	Severe pain in abdomen on and off	Doctor at referring hospital	Yes - everyone knows from both sides	No - too young	My wife helps but the doctors give more support- information	Not much change but more tired as need to visit after work	No problem with medical or nursing staff
CF - 49 Mini bus driver quit after child's diagnosis	14 M	Too sudden, cry, did not think it could be so serious	Lethargic, flu like symptoms	Private doctor and confirmed by specialist	Yes - except own mother - useless because of Alzheimer	He just know - I guess he figure it out himself	The doctors but the wife was too upset to give support	Not much, more tired work longer hours to bring in more money	Doctors are helpful- inform condition of child
DF - 44 Marine policeman	6 F	Too sudden, cannot believe, stay up at night, tired	Fever, sore throat	Doctor at hospital A	Yes - Did not tell own parents because too old	Partial truth - ill and needed to go to hospital	I keep telling myself it's going to be OK, the	Stay in hospital longer, came to visit after work	The doctors are helpful

							doctors help	- tired	
EF - 43 Truck driver	13 M	Shock, disbelief	Sunburn, fever, bruises	Specialist at hospital A	Yes- everyone knows including 88 year old father	Yes, overheard medical personnel	The doctors but wife try to give me support	I quit my job to be with him	I have no trouble with them - they did not give me a hard time
FF - 36 Businessman, owns import and export business	2 F	Too sudden, shock	Fever, cold	Doctor at hospital A	Yes, told everyone	No - too young - no point	Have to be strong for wife - help to talk with her but doctors help by giving information	Tired, visit after work cut down on eating out and did not entertain unnecessary	I have no problem they all seemed helpful especially the doctors - inform
GF - 29 Hairdresser - Owns business	5 M	Too sudden, cry , tired	Fever, pain in joints	Confirmed at treatment hospital	Yes	Partial truth - worms in stomach	The wife helps and the doctors	less time with the youngest child Tired - flexi hours at work	No problem - the doctors always tell us what is happening
HF - 28 Truck driver	11 month F		Rash on face, fever	At hospital A by the specialist	Yes	Too young - no point unable to understand - just a baby	Well my father and brother who live with me	Tired, into visit after work and need to get up early	They seemed OK to me

APPENDIX VI

Sample of Fieldnotes for mother - BM

Venue: BM's residence (WTS area)
Date: 3.4.94
Time: 14:00

*Physical set up of the residence:

Number of rooms in the apartment - 6

1 Master bedroom
2 bedrooms
1 living room
1 bathroom
1 kitchen

General information on the client:

Mrs. BM was 28 and had just moved to this new apartment less than a month previously.
She worked at a bank full time for over eight years and was the head of her section. She had been married for six years and had only one child. She was the only child in her family as well. Mrs. BM was well dressed, very pleasant, and appeared relaxed on the interview day.

I arrived at Mrs. BM's apartment at 14:15 as I had difficulty finding the right block.
I was greeted at the door by Mrs. BM and her daughter, T.M.
I introduced myself once again. When I sat down, she offered me a drink and a piece of cake.

She had known in advance that I was coming, and had asked her husband to buy some drinks and pastries.

The apartment was of a fair size for H.K. and was well kept and maintained by the maid.

Her daughter followed us everywhere, but she was well behaved and did not interrupt the interview.

The interview started at 14:30 and lasted till 16:00.

Mrs. BM did not have any reservations about answering any of the questions, she was very articulate and expressed herself fully. She did not show any emotional distress during the interview and appeared to have accepted the child's condition well.

Her relationship with the child T.M. appeared good. The child followed her around the apartment, was well behaved and did not interrupt the interview when asked not to.
The child sat next to the mother and clung to her closely at the beginning but later relaxed and started to walk around the apartment.

The mother appeared to have her eye on T.M. constantly when she was up walking around the apartment. However, this did not interfere with the data collection procedure as this did not happen until the interview was almost over.

At one point during the interview, the child wanted to have something to drink and asked for a glass of cola. Mrs. BM went to the fridge and poured T.M. a glass of beverage from the coke bottle, but later I was told that it was actually sugar cane juice. Mrs. BM smiled and said that T.M. was very smart and could recognise the coke bottle but could not distinguish the juice from the soft drink.

Mrs. BM was also very physical with her daughter, constantly hugging her.

Towards the end of the interview, she gave T.M. her congee and proceeded to feed it to her. She was very patient and made sure that the food was the right temperature before feeding to her daughter.

Throughout the whole interview, there were only minor interruptions and the phone did not ring once. I was later told that the phone was off the hook as Mrs. BM wanted minimal disruption during the interview.

I was glad that she had thought of that without me asking, but on the whole the taping of the interview went well, my tape recorder worked well and the battery did not go flat.

Throughout the interview, Mrs. BM appeared relaxed and maintained almost constant eye contact with me. All questions were answered and she showed no signs of fatigue or emotional distress during the taping. The presence of the recorder did not threaten her. I placed the recorder at a comfortable distance and she told me later that she had forgotten that I was taping the interview.

On the whole, the interview was a success. The only interruption came from the environment, as occasionally a plane would fly very low over the building but luckily this was not very frequent.

When I finished my interview, Mrs. BM saw me to the door and said good-bye. The child also waved.

Note:

Interviewing the parent at her apartment was certainly better than the hospital. Mrs. BM was more relaxed. Disruption could be controlled to a greater extent and this particular client had made an extra effort to ensure that interruption was minimal as well. It was a successful interview with a client who was willing to talk and all the equipment worked fine.

Sample of field notes for father - DF

Venue: Waiting area of hospital A's outpatient department

Date: 5.2.95.

Time: 10:00

Physical layout of the waiting room:

The total area was about 30 square meters and there were a total of 10 rows of benches in the area.

On the day of the interview, the child was coming to see the doctor to plan for admission the following week for the insertion of the central line.

When I interviewed Mr. DF, the child was with the mother in the other part of the waiting area, so there would be no interruptions from the child.

There were no interruptions from the child but there was a lot of disruption, the place was extremely noisy with people walking around and talking loudly and other patients being transported by wheelchairs.

The area was open and not confined, it was situated next to the outpatient x-ray department.

During the interview, the tape was stopped a couple of times because of the noise. I suggested to Mr. DF that we moved. Even though there was a lot of noise, Mr. DF did not have any problems expressing himself. Twice his thoughts were distracted by the noise and I needed to ask him the question again.

We moved to a less crowded place towards the middle of the interview. The area began to clear out and the other patients were all leaving. The noise level came down and there were also fewer people around. Mr. DF then started to show his emotions more.

Up to that point, he was using a matter of fact tone and had shown minimal emotion. (I was watching him closely for non-verbal cues). Once the place started to empty out , he was more talkative and started to cry at one time when asked about his daughter's treatment plan. I asked if he wanted to stop but he insisted on continuing and later stated that a chance to talk was what he needed.

The interview lasted a little over an hour, tentatively at first, but happily the pace of the interview picked up midway.

At the beginning of the interview, the client was a bit reserved and only answered the questions superficially. Later, he began to feel comfortable with the interviewer when I told him the purpose of the interview. Once he began to relax and there were fewer people around, he began to disclose more details about his personal experiences.

This interview was a success despite all the distractions. The client was eventually able to share his innermost feelings and I felt that besides obtaining information for the study. I had also provided an outlet for Mr. DF. to vent his feelings.

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